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CAREGIVERS' RELATIONSHIP SATISFACTION AND PERCEPTION OF COMPETENCY AS PREDICTORS OF QUALITY OF LIFE FOR ALS PATIENTS

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Dissertation Approval

This is to certify that the thesis presented to us by Jessica Stewart Allen on the 19th day of March, 2004, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Abstract

In addition to the physiological impact of Amyotrophic Lateral Sclerosis (ALS), patients and spousal caregivers experience significant emotional and psychological reactions to the disease and its course. As there is no effective treatment and no cure for this debilitating, fatal neuromuscular disease, treatment should include psychological interventions to improve patients' disease experience. External factors impacting psychological well-being of patients must be identified to allow for effective and relevant intervention. The current study examined the relationships between level of care provided to patients, caregivers' relationship satisfaction, and caregivers' perceived competence, and whether these factors predict patient quality of life (QOL). It was hypothesized that spousal caregivers' satisfaction in their relationships with patients, as well as their competence as caregivers, would predict ALS patients' QOL beyond level of care required and after various aspects of QOL (within five domains of functioning) were considered. Fifty three spousal ALS patient-caregiver dyads at a predominantly rural university hospital provided data during a multidisciplinary clinic. Caregivers completed the Dyadic Satisfaction Subscale of the Dyadic Adjustment Scale (DAS), Perceived Caregiving Competence Questionnaire, and Level of Care Index. Patients completed the McGill Quality of Life Questionnaire (MQOL), including the Single Item Scale (MSIS) to assess subjectively rated QOL. Correlational and hierarchical multiple regression analyses did not identify a predictive relationship between the hypothesized variables, but did indicate that patients' total MQOL score predicted 32.5 percent of the variance in self-reported QOL, and was the best predictor of this patient variable, as assessed by the MSIS [F (1, 47) = 24.06, p < .05]. This finding suggests that patients, when asked to do

so subjectively, accurately represent their QOL, as assessed more indirectly and by varied experiences. Further, QOL is more broadly defined for patients than is solely represented by the MQOL, and not largely dependent on caregivers. Additional research is needed to more accurately understand factors contributing to ALS patients' QOL and means to more precisely measure this construct. Future studies should aim to identify caregiver variables that may influence patient illness experience to justify additional intervention for both members of the spousal dyad in coping with ALS.

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Chapter 1: Introduction

Research exploring the experience of patients with Amyotrophic Lateral Sclerosis (ALS) has increased in recent literature, and includes investigations related to diagnostic considerations (Brooks & the ALS CARE Study Group, 2000), presentation (Abe, 2000; Barthlen & Lange, 2000; Desport, et al., 2000; Toepfer, Folwaczny, Reipl, Muller-Felber, & Pongratz, 1999), course (Neudert, Oliver, Wasner, & Borasio, 2001), psychosocial experiences (Rabkin, Wagner, & Del Bene, 2000; McNaughton, Light, & Groszyk, 2001), and treatment options (Common acne antibiotic, 2002; Desport et al., 2000; Sojka & Andersen, 1997). As no cure or effective treatment has yet been identified, a great deal of this literature has emphasized palliative care and the quality of life of ALS patients and their caregivers (Borasio, Voltz, & Miller, 2001; Bromberg & Forshew, 2002; Clarke, Hickey, O'Boyle, & Hardiman, 2001; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; Mitsumoto & Del Bene, 2000; Robbins, Simmons, Bremer, Walsh, & Fischer, 2001; Simmons, Bremer, Robbins, Walsh, & Fischer, 2000). As the presentation of ALS is pervasive, across physiological functioning, and rapidly progresses with certainty toward death, there are numerous potential factors to negatively impact the ALS patient's quality of life. Similarly, because of the significant demands placed on the caregivers of these patients, it is extremely likely that they, too, experience an increase in psychological distress as a result of ALS.

A great deal of research has reviewed the psychological impact of chronic illness on patients with cancer, hypertension and heart disease, diabetes, and arthritis (Andersen, 1992; Burckhardt, Woods, Schultz, & Ziebarth, 1989; Livneh, 2001; Newsome & Schulz, 1996) and on the caregiver (Grant, Elliot, Newman-Giger, & Bartolucci, 2001; Manne, Alfieri, Taylor, & Dougherty, 1999; National Family Caregivers Association, 2000; Schulz, Visintainer, & Williamson, 1990; Stebbins & Pakenham, 2001; Stephens, Norris, Kinney, Ritchie, & Grotz, 1988) separately, but few have investigated the relationship between these variables or the impact of factors related to one spouse on the quality of life (QOL) of the other partner. This study aimed to identify spousal caregiver variables that may influence ALS patient QOL. Specifically, spousal caregiver feelings of satisfaction in his/her relationship with the patient, and his/her feelings of competency as a caregiver, were examined to determine if these variables influence the degree of patient QOL.

The presentation, symptoms, and course of ALS are presented to exemplify the uncommon aspects of these patients' illness experiences as compared to other chronically and terminally ill populations, with additional emphasis on the psychological and psychosocial disturbance that may manifest as a result. Specific attention was paid to how these symptoms and the disease progression impact patients' psychological experience and resulting QOL. Next, the impact of ALS on caregivers was outlined, emphasizing the unique effects of this disease beyond the experiences of caregiving in general. As the caregiving experience is multifaceted, the literature pertaining to the effects and influence that caregiving has in the lives of those who assume that role was explored in an attempt to emphasize the impact those changes may then have on the caregivers' self-concept and interactions with the patients. Finally, QOL as a psychological construct and focus in behavioral medicine literature was explored, from definitions to measures developed for use with medically ill patients, to specific measures identified to be relevant (or irrelevant) for use with ALS patients. Some pertinent literature in the field of QOL research was presented to outline examples of factors that have been shown to mediate QOL as part of the illness experience, as well as other considerations for any chronically ill population. Literature presenting specific research within the ALS population related to QOL was discussed to provide studies for comparison for this investigation.

Statement of Objectives

1. To identify whether or not spousal caregiver variables, such as relationship satisfaction and self-perceived competence in the role of caregiver, influence the QOL of ALS patients.
2. To contribute to the existing ALS literature by assessing self-reported QOL of patients and how it may be influenced by their required level of care, their indirectly assessed QOL, and those caregiver variables under investigation.

Prevalence and Cause of Amyotrophic Lateral Sclerosis.

ALS is a neurodegenerative, fatal disease characterized by progressive motor neuron destruction, muscle weakness, loss of function, and ultimate respiratory failure (Bromberg, Anderson, Davidson, & Miller, 2001; Rabkin et al, 2000; Sojka & Andersen, 1997). Regardless of geography, culture, climate, or race, ALS appears to present uniformly worldwide, with an incidence of roughly 1 to 2 in every 100,000 annually (Mitsumoto & Munsat, 2001), new diagnoses every 24 hours totaling 15, and 15 patients dying with ALS every 24 hours (Amytrophic Lateral Sclerosis Association, 2001; Common acne antibiotic, 2002; New legislation, 2001). The prevalence of ALS — the number of patients with the disease at a given time — in the United States is roughly 30,000 people (ALS Association, 2001). Men appear to be at a somewhat higher risk for developing ALS, though this gender difference seems to decrease with age (Mitsumoto & Munsat, 2001). ALS is acquired either sporadically (roughly 90 percent to 95 percent of patients) or genetically (5 percent to 10 percent of patients with an inherited form of the disease, known as familial ALS). However, only a small percentage of those with familial ALS (FALS) have been identified with a genetic defect (Mitsumoto & Munsat, 2001).

ALS "clusters" have been documented, whereby multiple diagnoses have been made within a very close geographic proximity in a short period of time (i.e., three gentlemen living in the same apartment building all diagnosed within 18 months; three unrelated men living within a block of one another) (Mitsumoto & Munsat, 2001). Due to these reported concentrations of the disease, as well as other studies investigating commonalities in ALS patients, environmental toxins or transmissible and/or infectious causes have been speculated (Brooks, & the ALS CARE Study Group, 2000; Mitsumoto & Munsat, 2001). The ALS Clinical Assessment, Research, and Education (ALS CARE) program was established to identify and characterize a broad, national spectrum of ALS patients, as well as identify common characteristics of these patients that may lead to the subsequent identification of possible risk factors for the development of ALS. The ALS Health Profile Study (ALS HPS), a similar group, was established in Europe. Although no specific cause for ALS has been established, research within the past decade has begun to identify feasible explanations that may guide further research and, hopefully, aid in treatment: such as the identification of a defective gene in familial ALS, deficiency of a specific glutamate transporter protein in the motor cortex and spinal cord, and the role of oxidative stress in motor neuron death (Siciliano, et al., 2002).

Treatment

Despite a significant increase in research related to causes and treatments of ALS in the last three decades (Mitsumoto & Munsat, 2001), there is currently no cure and no effective treatment to stop the progression of the disease. More than 60 medications (as well as some non drug therapies) have been evaluated in therapeutic trials and found to be ineffective in changing the natural course of ALS, including antiviral agents, immunomodulating agents, and chemotherapies (Mitsumoto & Munsat, 2001). Thus, most available therapies for ALS are directed toward symptom management, maintaining independence, and issues of quality of life (ALS Reporter, 1997; Desport, et al., 2000; Mitsumoto & Munsat, 2001).

A significant breakthrough in the treatment of ALS came in 1994 when riluzole was found to prolong the survival of ALS patients (Mitsumoto & Munsat, 2001). The only drug approved for ALS by the US Food and Drug Administration, riluzole is a neuroprotective agent that presynaptically inhibits the release of glutamate (Sojka & Andersen, 1997). On average, riluzole was found in two placebo-controlled, double-blind trials to extend survival for ALS patients 2 to 3 months (Bensimon, LaComblez, & Meininger, 1994; LaComblez, Bensimon, Leigh, Guillet, & Meininger, 1996). Sojka and Andersen (1997) investigated the effectiveness of riluzole in altering the natural course of symptom deterioration (according to the linear regression equation identified by the TQNE protocol) in five patients with ALS. The patient response in their study varied, adding further evidence that, although riluzole has been identified as effective in numerous patients, ALS patients are not a homogenous group and the efficacy of riluzole (and other drugs) may not be consistent across patients. There are a number of other drugs currently in active clinical trials but, until a new drug is identified that more uniformly and consistently alters the course of this illness, treatment must incorporate other interventions to improve the experience — and QOL — of ALS patients.

When dissatisfied with conventional medicine, patients and physicians often seek alternative and holistic approaches to treatment, including nutritional regimens, vitamins, antioxidants, therapeutic massage, and visual imagery. Even if the course of the illness is not altered and physiological functioning is not successfully addressed, these interventions may provide some symptom relief, and, therefore, provide additional benefit through improving psychological well-being (in that they offer patients a sense of mastery over at least some aspects of the disease) (Mitsumoto & Munsat, 2001). In addition, nutritional management is gaining attention as a treatment option, as malnutrition has been identified as an independent factor in prognosis (Desport et al., 2000). Further, as a supportive treatment nutritional management may noticeably improve the quality of the ALS patient's life by reducing discomfort, such as that caused by constipation.

The Course of ALS

Life expectancy, although variable, is typically between 3 and 5 years after the onset of symptoms, with 8 percent to 16 percent of patients surviving beyond 10 years (ALS Association, 2001; Mitsumoto & Munsat, 2001; Sojka & Andersen, 1997). Initial presentation of symptomatology and ultimate progression of the disease varies among patients, based on which motor systems (arms, legs, speech, swallowing, etc.) are most affected. What is certain, however, is that ALS is debilitating and fatal.

Classification. ALS can be classified according to the motor neurons affected and resulting symptom presentation (Mitsumoto & Munsat 2001). Classic ALS is a presentation of symptoms that result from both upper and lower motor neuron impairment, while some ALS patients present with symptoms specific to either upper or lower motor neuron loss but not both. Primary lateral sclerosis, a rare syndrome, occurs when only the upper motor neurons are affected and presents with symptoms of limb stiffness or spasticity without weakness or atrophy. Some patients with this initial presentation will develop more classic symptoms of ALS later (Mitsumoto & Munsat, 2001). Progressive muscular atrophy is the term applied when only lower motor neurons are affected and presentation includes severe muscle wasting and weakness and loss of reflexes. In addition, some patients may present with symptoms in only one region, such as speech and swallowing as in the case of bulbar onset, which accounts for approximately 20 percent to 30 percent of all cases (Borasio et al., 2001; Mitsumoto & Munsat, 2001).

Initial symptoms of classic ALS. The initial symptoms of classic ALS include "exaggerated reflexes, or spasticity, along with weakness and wasting of facial, limb, or respiratory muscles" (Mitsumoto & Munsat, 2001, p. 10). In addition, common initial symptoms include muscle twitching and cramping, impaired use of limbs, unusual fatigue and weakness, or difficulty walking (Brooks & the ALS CARE Study Group, 2000; Mitsumoto & Munsat, 2001). Less common initial symptoms include weakness of the neck or respiratory problems, weakness in only one side of the body, pain, and weight loss. Muscle weakness is the first symptom noticed for nearly 60 percent of patients (Mitsumoto & Munsat, 2001), while muscle cramping "is one of the most common symptoms in the early stages of the disease," occurring in 80 percent to 90 percent of patients (Mitsumoto & Munsat, 2001, p. 21).

Progression of symptoms. Physical symptoms typically progress to include loss of dexterity, weakness and atrophy, spasticity with exaggerated reflexes, and then a disinhibition of primitive reflexes (such as the Babinski sign), muscle cramps, muscle fasciculations (fine twitching), difficulty controlling saliva, weight loss, fatigue, speech disturbance, difficulty in chewing and/or swallowing, and distressed breathing or respiratory insufficiency that ultimately leads to death (Barthlen & Lange, 2000; Borasio et al., 2001; Mitsumoto, & Munsat, 2001). In addition, patients often experience other, indirect symptoms with ALS, such as sleep disturbance (due to inability to move and get comfortable or psychological disturbances), nutritional deficits due to eating problems, drooling, or pain (Borasio et al., 2001). Gastrointestinal motor functioning in ALS patients was recently studied to identify the possibility that, although they do not complain of symptoms, patients may be experiencing delayed gastric emptying and disturbed gastrointestinal transit (Toepfer et al., 1999). This is clinically relevant not only for the specific findings of that study (that food intake may be reduced if these problems are present, resulting in further issues of weakness and malnutrition) but also because it exemplifies the possibility that ALS patients may be experiencing secondary physiological dysfunction as a result of their primary symptoms. In addition, these findings suggest that patients' symptomatology (physiological, and perhaps psychological) goes unnoticed and further negatively impacts their quality of life.

Although symptoms may potentially become pervasive, bowel and bladder function, eye muscles and vision, and sensation are usually unaffected (Borasio et al., 2001; Mitsumoto & Munsat, 2001). There is debate in the literature regarding the extent of cognitive deterioration that accompanies ALS, but the consensus has been that dementia in patients with ALS is relatively rare (Borasio et al., 2001; Common acne antibiotic, 2002; Mitsumoto & Munsat, 2001). Neuropsychological deficits, particularly frontal lobe dysfunction, often are present in examination; however, severe dementia is rare. In addition, impaired verbal, attention, or memory abilities (Abe, 2000; Mitsumoto & Munsat, 2001) may be due to other factors related to affective disturbance or the age process itself (as a significant proportion of ALS patients are older adults) (Borasio et al., 2001). On the other hand, dementia may not be detected in ALS patients, especially those with bulbar palsy, due to physiological deficits that may make assessing mental function difficult (Abe, 2000; Mitsumoto & Munsat, 2001). While behavioral and psychotic changes are rare, symptoms of dementia in ALS patients may include confusion, personality change, and memory problems. However, these symptoms also accompany a diagnosis of depression, and may be misdiagnosed as dementia. In fact, because ALS produces so many physiological, social, and functional changes for patients, one of the most common psychological problems for ALS patients is depression (Mitsumoto & Munsat, 2001).

Of note with regard to this debate over the presence of cognitive decline associated with ALS, Lomen-Hoerth and colleagues (2003) more recently presented findings that are contradictory to existing literature when investigating the presence of dementia, specifically frontotemporal lobar dementia, in ALS patients. Of the 100 ALS patients assessed by the Mini-Mental Status Examination (MMSE) and an initial word generation task, 44 patients were given additional neuropsychological testing to identify frontal-lobe executive deficits, including changes in personality, behavior, planning, language, self-monitoring, and emotional regulation. Findings revealed that 23 of the 44 patients had possible or probable frontotemporal lobar dementia and that, in particular, bulbar-onset ALS patients were more likely to evidence abnormal performance on the word generation test in the initial screening than other patients (Lomen-Hoerth, et al., 2003). This may be due to the fact that patients' responses were given either verbally (something of a challenge for bulbar patients), in writing, or typing, and that these modes of communication may be more or less difficult from patient to patient — especially in a population whose mean age is 65 years old and who may or may not be adept at using (or able to use) electronic communication devices.

Avenues to Improve ALS Patient Experience

Recent increased focus on ALS has explored risk factors, causes, treatments, and specific physiological changes of the disease such as gastrointestinal dysfunction, sleep disturbance, and malnutrition (Barthlen & Lange, 2000; Brooks & the ALS CARE Study Group, 2000; Desport et al., 2000; Toepfer et al., 1999), and also psychosocial aspects of the patient's experience, such as financial hardship, employment problems, and limited social involvement, that contribute significantly to the ALS patient's quality of life (McNaughton et al., 2001; Rabkin et al., 2000). In July, 2001, the U. S. Congress passed a law that eliminated the 24-month waiting period for Medicare coverage for ALS patients (New legislation, 2001). Until this law, patients with ALS were waiting nearly 29 months after their Social Security Disability application was approved before seeing the financial assistance of Medicare benefits. For a patient with ALS, whose life expectancy may not even be 2 years, this increasing recognition and assistance by government may help to ease the concern for financial stability, helping to improve patients' quality of life.

In a study by McNaughton and his colleagues (2001), the employment experiences of five ALS patients were explored via a focus group discussion in an attempt to identify benefits and consequences, reasons for, and barriers to continued employment. In addition, supports required for ALS patients to promote successful employment and recommendations to employers, government, assistive technology manufacturers, and others with ALS were identified and recommended. Of specific interest here, these researchers found that patients expressed the need for employment because it allowed for productive activity, a means to avoid thinking about ALS, a way to feel like a contributing part of a whole, a sense of identity with the profession as opposed to a "patient," positive workplace experiences, and the practical benefits of employment (such as income) (McNaughton et al., 2001). Most of the barriers related to physical abilities, supports and (technical) assistance, insurance, and medical issues, lending support for research to focus not simply on medical advances but on advances in overcoming barriers to continued vocational and independent functioning. Although, due to the small sample size, McNaughton and colleagues' study is not representative of ALS patients overall, it does emphasize the necessity of investigating aspects of the ALS patient's experience beyond physical symptomatology until a cure or effective treatment can be identified. It emphasizes the need for future research to focus on aspects or factors that influence the ALS patient's quality of life for the sake of its improvement.

Psychological Considerations

Adaptation. Adaptation to chronic illness and disability is crucial to a patient's quality of life and is influenced by multiple factors, some as alluded to above, including internal and external, antecedent and contextual, and interpersonal, intrapersonal, and extrapersonal/community-based variables (Livneh, 2001). In Livneh's (2001) model of psychosocial adaptation, multiple contextual factors influence the adaptation process for patients facing illness and disability — and ultimately the quality of life of patients — and include: 1) variables associated with the illness/disability itself (i.e., type and severity of symptoms, functions affected, impact of illness on appearance, pain, and functional limitations); 2) variables associated with sociodemographic characteristics of the patient, such as age, gender, sex role identification, education, and occupation; 3) personality or psychological attributes (i.e., self-concept, self-efficacy, perceived sense of control or mastery, ego strength, optimism, body image, emotional arousal, cognitive ability, and personal loss); and 4) external environmental characteristics, such as social isolation, limits to mobility, social support systems, and financial resources (Livneh, 2001).

The relevance of presenting this model in a discussion related to quality of life of ALS patients relates to the emphasis of adjustment factors beyond those related to the illness itself, and the inclusion of environmental, social, and psychological experiences of the patient. ALS presents an uncommon set of illness experiences, different than other chronic illnesses or disabilities, in that the process of adaptation that these patients (and their families) must navigate is ongoing. It is not a one-time adjustment following the onset of the illness or diagnosis, but one requiring continuous readjustment to a rapidly, progressively worsening condition (Mitsumoto & Munsat, 2001). The adaptation required to adjust to a diagnosis of ALS is unlike that of conditions such as diabetes, hypertension, or arthritis, because the process of adjustment in these illnesses allows patients to effectively cope for a period of time after each adjustment and prior to the need to adapt again (as their condition progresses, complications occur, etc). In addition, ALS patients' knowledge that their adjustments are only in an effort to cope temporarily (and not improve their chances of survival) may produce a much different psychological response than, for example, adapting to a permanent, life-long disability following an accident or adjusting one's lifestyle to effectively cope with diabetes. Livneh's model allows for the continually changing nature of these factors in the ALS patient experience by indicating that these variables serve as "moderating, mediating, or interacting variables that impact the nature, expression, pace, valence, and sequencing" of psychosocial reaction to illness and disability (Livneh, 2001, p.154), throughout the course of the disease.

Issues of psychological and psychosocial functioning in ALS patients assume a priority emphasis, whereas in other chronic illnesses change in patient behavior or nutritional regimen (as with diabetes or heart disease) and treatment options (such as with the diagnosis of cancer) are paramount. Although some patients diagnosed with terminal cancer are also faced with rapid progression, inevitable death, a lack of treatment options, and total physical disability, all patients do not with certainty experience these difficulties as in the case of ALS.

Psychological Symptoms. If not all, at least most ALS patients experience depression in response to diagnosis (Borasio et al., 2001) and to the inevitable experiences of ALS. Studies have indicated that many patients may experience psychological distress in response to the loss of autonomy, control, independence, or ability to engage in previously pleasurable activities anymore (Ganzini & Block, 2002; Mitsumoto & Munsat, 2001; Rabkin et al., 2000). Although most of these patients do not meet criteria for major depression according to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (American Psychiatric Association, 1994), self-reported (and medical team identified) symptoms of depression are present in 44 percent to 75 percent of patients (Borasio et al., 2001; Ganzini et al., 1998; Rabkin et al., 2000). It has also been reported that ALS patients who were more physically disabled were more depressed, while those with specifically worse speech problems were more anxious (Rabkin et al., 2000).

In addition to depression, psychological and psychosocial disturbance seen in ALS patients (that many other chronically ill patients do not experience) may relate to the inevitable and permanent loss of independence, the inability to maintain employment or recreation, a decrease in social activities, loss of mobility and possibly speech, the inability to care for themselves or even breathe on their own, uncertainty of the course of their illness, and the knowledge of their inevitable death (Mitsumoto & Del Bene, 2000; Mitsumoto & Munsat, 2001). According to a review by Rabkin and colleagues (2000), there are contradictory findings in the literature related to the adaptive function of denial—with some studies reporting that denial has aided in reducing depression, while still others have indicated that less reliance on denial and a greater acceptance of their illness resulted in less depression. This inconsistency may be due to an inadequate sampling size and/or recruitment bias that may be the case in other studies of ALS patients because recruitment usually consists of small clinic samples or survey responses (Abe, 2000; Barthlen & Lange, 2000; McNaughton et al., 2001; Toepfer et al., 1999).

Rabkin and colleagues (2000) investigated patient and caregiver distress and correlates of each in the ALS population. They indicated that protective factors have been established to include religious faith and family or other social support, while risk factors include illness symptoms, pain and suffering, and perceived family burden (Rabkin et al., 2000). In their study, 49 ALS patients and 25 caregivers were assessed on measures related to psychopathology, depression, physical fatigue, hopelessness, attitudes toward hastened death, quality of life, and spirituality. According to their findings, 12 percent of patients had clinical depression, as assessed in structural clinical interview. Depression assessed via the Beck Depression Inventory (BDI) indicated a sample mean of 11.6 (SD = 8.3) which, although in the mild range, is higher than the general population. Significant depressive symptoms are assessed as scores greater than 13, which in this sample describes 28 percent of patients. With regards to anxiety, the mean score on the Spielberger Trait Anxiety Inventory (STAI) was 40 (SD = 11), which is higher than the norms for both genders (34 for males and 32 for females) for this age range (Rabkin et al., 2000). Both depression and anxiety scores highly and inversely correlated with life satisfaction scores ($r = -0.65$, $p < 0.05$), indicating that the majority of patients with higher depression and/or anxiety scores also had lower ratings of QOL. In addition, the mean score for this sample on the Beck Hopelessness Scale (which is a construct indicative of the presence of depression and on which patients with major depression have been normed to score a mean of 10), was 7.9 (SD = 5.2). Thirty-percent (N = 18) of patients in this sample had scores indicating moderate depression, while 13% (N = 6) had scores in the severe range of depression (Rabkin, et al., 2000). These findings clearly support previous claims that, although ALS patients do not necessarily exhibit clinical depression, many experience psychological symptoms, such as depression and anxiety, to significant degrees.

As physical symptoms worsen and patients become increasingly more debilitated, their abilities to engage in employment, household responsibilities, and even self-care are drastically reduced. The inability to engage in previously possible tasks — especially necessary tasks that are representative of independence, such as self-care — may result in feelings of helplessness, a reduction in self-worth, an altered image of self as less than a productive adult, and concerns about being a burden to loved ones. These symptoms (many that relate to depression) may further result in patients withdrawing from loved ones and friends in an effort to reduce embarrassing physical symptoms or reliance on others. This social isolation may further strengthen patients' depressive symptoms and result in an experience that they are alone in their disease. Patients may also experience significant guilt or anger related to burdening their loved ones, whether financially (due to the inability to work and costs related to care) or directly related to caregiving needs.

Due to the nature of ALS, the lack of effective treatment, and absence of a cure, patients may begin to experience feelings of hopelessness, anxiety about the progression of their illness (such as concerns about pain) and about death. Some patients may fear choking to death due to a loss of bulbar function, thus an increase in anxiety may be experienced. Knowing what lies ahead, many patients may begin to question their ability to cope with their illness (Mitsumoto & Munsat, 2001). As there is no known cure, patients may have nothing to maintain optimism or hope and may experience learned helplessness, whereby they lose motivation, are less socially responsive, become anxious, and further depressed due to an inability to escape or alter a physically and emotionally stressful situation. Some patients begin to consider physician-assisted suicide as a viable means to end their physical (and especially) psychological suffering, or to avoid being a burden to their family (Borasio et al., 2001; Ganzini et al., 1998). In one study, 56 percent of patients agreed with a statement that under some circumstances they would consider action that would end their lives (Ganzini et al., 1998). Those patients agreeing with this statement also showed higher scores of hopelessness, less likelihood for religiosity, and lower self-rated QOL. There was no difference in depression between these patients and those who would not consider taking a lethal dose of medicine. Despite expressed consideration for taking steps to end one's life, Neudert and colleagues (2001) report that incidences of suicidal actions are relatively rare in ALS. This is not so, according to Ganzini and Block (2002), who report that ALS patients are more likely to request physician-assisted death than other patients with terminal illnesses. In Oregon, following the legalization of physician-assisted suicide, five percent of all ALS patient deaths in 1999 were from assisted-suicide, as compared to the 0.4 percent among patients with cancer (Ganzini & Block, 2002; Sullivan, Hedberg, & Hopkins, 2001). Although depression has been shown to be associated with the desire for assisted-suicide in cancer patients, no relation between level of depression and interest in hastened death was found in ALS patients (Ganzini et al., 1998).

Not all psychological changes ALS patients undergo are negative or further debilitating. Many patients report a new appreciation for family, friends, health, and life itself (Mitsumoto & Munsat, 2001). This suggests that, despite the above-noted negative differences between ALS and other chronic illnesses and disabilities, ALS patients are capable of successful adaptation to their illness, even if that is an ongoing process and requires the assistance of environmental support.

Caregiving Needs

Although each patient differs in the rate of progression through the course of ALS, as a result of the inherent and cumulative physiological impairments caused by the disease, patients will become dependent on caregivers for assistance with basic daily living tasks, mobility, medical regimen, and support (Mitsumoto & Munsat, 2001). In addition to the adaptation discussed above, if the caregiver of the ALS patient is a family member, then relationship dynamics will have to adapt to the illness as well. Specifically, adaptation in the relationship between patient and loved ones will require adjustment to the changing dependency needs of the patient and the physical and emotional demands these needs place on the caregiver. This adaptation, then, likely produces further (beyond the disease itself) psychological response in both the patient and caregiver (and other family members). As the caregiver experiences the patient's course and disease progression, that caregiver likely undergoes his or her own psychological changes.

If the caregiving family member is a spouse or life partner (from here forward referred to as spousal caregivers), this relationship change may be more significant — though not necessarily in a negative direction — because both the caregiver and the patient may experience changes in affective, cognitive, and behavioral functioning in response to the disease and to each other's struggles. As well, marriage (and cohabitation) is a unique relationship because of the interdependence, reciprocal nature, intensity, and intended duration it creates and presumes (Goodman & Shippy, 2002; Manne et al., 1999). The potential for each spouse's psychological response to affect the other is inevitable—as relationships are reciprocal, so is the impact of disease, illness, and disability. For 78% of ALS patients the primary caregiver is the spouse (ALS Association, 2001), making this issue of impact of caregiving on spouses one of primary concern with this population.

Caregiving Experience

A great deal of research in the literature has investigated the physical, psychological, and social relationship between physical and psychological status of caregivers as a result of their role and responsibilities to patients (Chou, LaMontagne, & Hepworth, 1999; Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Gallant & Connell, 1998; Haley et al., 1995; McClenahan & Weinman, 1998; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000; Pearlin, Mullan, Semple, & Skaff, 1990; Pruchno, Kleban, Michaels, & Dempsey, 1990; Schulz & Beach, 1999; Schulz et al., 1990; Stebbins & Pakenham, 2001; Stephens et al., 1988; van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). Although the majority of studies investigate caregivers of patients with Alzheimer's disease and dementia, the interest here regards findings that relate to caring for chronically ill patients.

The consensus indicates that the task of caregiving for patients experiencing chronic illness produces a number of psychological changes within the caregivers that vary in severity and are moderated by a number of factors. Numerous studies have been guided by a stress process framework — the perspective that caregivers experience certain stressors and demands that are mediated by variables such as personal orientation, caregiver appraisal of stress, coping style and skills, problem-solving abilities, self-efficacy and perceived competency, and social support (Ben-Zur, Gilbar, & Lev, 2000; Coppel, Burton, Becker, & Fiore, 1985; Dorfman, Holmes, & Berlin, 1996; Goodman, Zarit, & Steiner, 1997; Grant et al., 2001; Minnes et al., 2000; Newsom & Schulz, 1996; Radina & Armer, 2001; Stephens et al., 1988;). In addition to the psychological and psychosocial changes that caregivers experience, several particular mediators are emphasized here as important in determining the caregiver's well-being and QOL, as it is relevant to this investigation of the reciprocal nature of these changes within the patient-caregiver relationship and, ultimately, the patient's QOL.

Psychological and Physical Impact on the Caregiver

The well-being of caregivers is an important focus area for any investigator interested in patient experience, because patients depend on those caregivers to maintain their own well-being, functioning, and adjustment to illness (Dennis et al., 1998). The literature has provided numerous, well-established findings related to caregivers experiencing increased levels of depression, anxiety, reductions in self-worth, decreased social activity, familial strain, effects on life satisfaction, a decrease or breakdown in relationship satisfaction, and physical health problems, as well as caregiver specific experiences of burden and strain (Ben-Zur et al., 2000; Dennis et al., 1998; McClenahan & Weinman, 1998; Pearlin et al., 1990; Pruchno et al., 1990; Schulz et al., 1990; Stephens et al., 1988). Those studies exemplifying the psychological and psychosocial changes experienced by caregivers of chronically ill patients will be outlined. Perhaps an initial source for this review is one summation conducted by Schulz et al. (1990).

Schulz and colleagues (1990) reviewed the empirical literature available to identify prolonged and cumulative consequences of caregiving stress, morbidity effects (physical and psychological), and the assessment measures commonly used to identify these. Morbidity was defined broadly, so that the valuable findings from studies using self-report as well as more formal clinical diagnoses could be included. Although they did not include studies that utilized measures of caregiver distress or burden, or effects of caregiving on relationships as outcomes, this collection of findings is valuable to indicate the areas of caregiving issues considered most relevant in the literature (other studies will be reviewed regarding this important issue of impact on relationship). In addition, this review by Schulz and colleagues (1990) was conducted 14 years ago and, therefore, findings within their summary are potentially outdated. This is not to say irrelevant, but consideration must be made when interpreting these summation results.

To summarize briefly, Schulz et al. (1990) found that depression was the most commonly studied psychological symptom among caregivers, assessed by 10 different measures across various studies. In addition, "most studies using standardized instruments show elevated depression rates among caregivers when compared to either age- and gender-based population norms or non caregiving controls" (Schulz et al., 1990, p. 185). Three conclusions were drawn from findings using the two most frequently documented instruments: the Beck Depression Inventory (BDI) or the Center for Epidemiologic Studies Depression Scale (CES-D): female caregivers tend to be more depressed than male caregivers, depressive symptoms were greater among caregivers of more severely impaired patients, and, lastly, subjects more representative of the relevant caregiving population will evidence lower depressive symptomatology (Schulz et al., 1990). This latter finding relates to sampling and the bias that may exist when participants seeking assistance for distress or responding to invitation to participate are included instead of caregivers identified and recruited through compiling all possible patients of a given illness first. These authors stressed the importance of interpreting the massive amount of caregiver data carefully, considering possible sampling and measurement biases, limitations to findings, and the possibility that normal reactions to caregiving (such as grief, hopelessness at times, or despair) may be confused with clinically significant symptoms that may skew results (Schulz et al., 1990).

Other findings summarized by Schulz and colleagues (1990) include higher levels of anxiety reported among female caregivers, higher levels of hostility (assessed by the Brief Symptom Inventory, BSI) among older men and women and younger women, and, on average, higher levels of psychiatric symptomatology in studied caregivers than in appropriate comparison groups. Although this review lacks consistent or abundant data to validate the suggestion that caregivers experience emotional and possibly physical distress as a result of caregiving, it does identify sources of possible contradiction in the literature and considerations for reviewing findings. It is both clear that caregiving provides for a stressful set of circumstances, and logical to assume these factors may contribute to a change in psychological functioning of the individual caregiver.

Of significant interest in this review by Schulz and colleagues (1990) is their emphasis on the potentially positive influence that caregiving may have on caregivers' well-being and their relationship with the patient. First, when considering effects of psychological distress on caregiver health status, most caregivers are married and marriage, itself, is a "selection factor for better health" (Schulz et al., 1990, p. 189). Second, some caregivers may receive greater benefits from caregiving than others, providing them with a "buffer" (or even positive influence) against the stress of caregiving. In particular, many caregivers report that their duties afford them a useful role, while other spouses have indicated caregiving offers a positive influence to their self worth. One final speculation is that caregiving may also improve the relationship between the patient and caregiver (Schulz et al., 1990).

To return to the issue of distress experienced by caregivers, McClenahan and Weinman (1998) investigated the determinants of caregiver distress in 86 stroke patient-caregiver dyads, assessing caregivers (primarily spousal) on measures related to general psychological distress, illness perception, optimism, generalized self-efficacy, coping strategies, social support (perceived and actual, practical and emotional), and measure of self-reported physical health. Patients were assessed on measures related to activities of daily living (ADL's), intelligence (via a measure suitable for this population with language dysfunction), aphasia and language tests, and self-reported mood. One finding related to determinants of caregiver mood included a significant, though small, (r = -0.29, p = 0.009) negative correlation between caregiver distress and level of patient disability (the lower levels of ADL scores, the higher the caregiver levels of distress) (McClenahan & Weinman, 1998). Additional findings related to determinants of caregiver distress include significant correlations between distress and: "generalized self-efficacy (r = -0.41, p = 0.000), coping strategy of venting (r = 0.31, p = 0.006), the coping strategy of suppression (r = 0.31, p = 0.006), illness perception factor of "timeline" (r = 0.28, p = 0.009), optimism (r = -0.33, p = 0.003), and self-rated physical health (r = -0.35, p = 0.002)" (McClenahan & Weinman, 1998, p.141). Upon multiple regression analysis, these variables accounted for 45 percent of the variance in caregiver distress, four of which were significant: generalized self-efficacy, the illness perception factor timeline, and the two coping strategies of suppression and venting.

These findings suggest that the distress caregivers may feel relates more to their own characteristics or variables than to those of the patients. Of significance here is the correlation between caregiver self-efficacy and distress, indicating that caregivers' with a higher sense of self-efficacy have lower levels of distress. Also, if caregivers who cope by venting experience higher levels of distress, it may be possible that the patients they care for do as well. This assertion is based on the possibility that the caregivers may be venting in the presence of the patients, thus including them in the effects of this coping strategy. This, of course, is a very loose speculation but one worthy of further investigation and a relevant consideration to this study. Regardless of whether distress experienced by caregivers relates to caregiver or patient variables, a high level of emotional disturbance is likely to result in the reduction of caregiver resources available to support the ill patient and, therefore, the patient may suffer (Ben-Zur et al., 2000).

Pearlin and colleagues (1990) talk about the "intrapsychic strains" of caregiving, as those related to dimensions of the self and psychological states. Specifically, positive elements of the self, such as self-concept, may be damaged by the stress of caregiving as the demands of the role expand, persist, and progress. People are more likely to suffer symptoms of depression and be more vulnerable to stress outcomes when this happens.

In addition to the experience of emotional strain itself, some research has speculated that the emotional disturbance produced by caregiving may result in health problems for the caregivers (Pruchno et al., 1990). Although a significant amount of the literature has emphasized the susceptibility for physical illness that depression and other emotional symptoms may create, cause-effect relationship has not been established between psychological and physical impact on caregivers. Pruchno and colleagues

(1990) investigated the relationships between depression, physical health, and burden among 198 caregivers of Alzheimer patients. Although a sample of convenience and not necessarily representative of the total population of caregivers (this sample was primarily white, female, and voluntary), findings provide support for the idea that physical health may be negatively impacted by depression over a relatively short period of time (6 months) (Pruchno et al., 1990). A second significant finding, although less consistently identified, is that depression also predicts the caregivers' subjective experience of burden. Gender differences were evident in these findings, in that the relationship between depression and physical health was not evident in male caregivers. This may relate to the smaller number of men in the study (60, to 138 females) (Pruchno et al., 1990), to bias in reporting symptoms, or to gender differences in somatization.

Inconsistent with the findings of McClenahan and Weinman (1998) and those summarized by Schulz and colleagues (1990), amount of assistance provided by the caregivers alone had little effect on burden, depression, or physical health, either at one time interval or across time (Pruchno et al., 1990). Pearlin and colleagues (1990) also reported an insignificant relationship between magnitude of caregiving work *alone* and caregiver emotional distress; however, when the demands on the caregiver are coupled with resistance from the patient, stress is more likely to result (Pearlin et al., 1990). This identifies a significant consideration in discussing the impact of caregiving on the caregiver — the importance of patient variables. If it is possible for patient factors, such as emotional state, to influence the experience of caregivers, then perhaps it is possible in the reverse.

In one investigation exploring the possible patient or caregiver characteristics that predict emotional distress in caregivers of stroke patients, Dennis and colleagues (1998) found, contrary to other findings (Pearlin et al., 1990; Pruchno et al., 1990) and consistent with McClenahan and Weinman (1998), that caregivers whose patients were more severely disabled (having higher dependency needs) experienced significantly more overall distress ($p < 0.05$), but not higher levels of (specifically) anxiety related to patient level of dependency. In addition, caregivers had worse outcomes of anxiety and depression when their patients were dependent before the stroke, than caregivers whose patients were independent prior to stroke ($p < 0.002$) (Dennis et al., 1998). Perhaps the duration of patient dependency has a cumulative effect on the emotional status of caregivers. Finally, and of greatest significance to this present investigation, is the finding that "caregivers' emotional outcome (both depression and anxiety) was associated with the patients' emotional status" (Dennis et al., 1998, p.1871). In interpreting their results, these researchers speculated that perhaps the patients' status influenced that of the caregivers, but also questioned that perhaps the opposite may be true — that the caregivers' emotional status influenced the patients' (Dennis et al., 1998). These findings support other patient-caregiver research (Bookwala & Schulz, 1996; Gaelick, Bodenhausen, & Wyer, 1985; Manne, Taylor, Dougherty, & Kemeny, 1997; Tesser & Beach, 1998; and Williamson & Schulz, 1990) related to the phenomenon of emotional convergence — that one person's emotional status (level of depression, adjustment to illness, etc.) may negatively (or positively) influence the emotional status of the other — the very hypothesis under investigation here and a topic explored in greater detail later.

Relevance to Caregivers of ALS Patients

The uncommon aspects of ALS, its course, and the resulting needs of the patients produce an equally uncommon experience for informal caregivers of this population, as compared to caregivers of other chronically ill patients. Most of the suggested impact of caregiving on the emotional distress of caregivers presented above in other populations holds true for those caring for patients with ALS. Neudert and colleagues (2001a) found (as part of a larger study already presented) that 33 percent of ALS caregivers in their sample reported feeling stressed frequently because of caring for the patient, and 12 percent had become ill while providing care for these patients. The suggested reciprocal influence of patient and caregiver psychological experiences discussed above is also relevant to this population. However, there may be some different considerations that caregivers of ALS contend with that other caregivers do not, that influence their caregiving experience, either positively or negatively.

The progressive, rapid nature of the disease requires continuous psychological adaptation by caregivers *in addition* to that described for the patients (Mitsumoto & Munsat, 2001). Caregivers also must accept and adjust to the knowledge that the course of ALS is with certainty downhill (although cases vary to some degree), they do not have a potential source of optimism, as some caregivers of patients with other illnesses, such as cancer, may when having options of surgery and treatment. As the patient deteriorates, there is an ongoing experience of loss for the caregivers (Mitsumoto & Munsat, 2001). Because there is no effective treatment for the disease, there may be a greater sense of lack of control for ALS caregivers than in the case with other illnesses who may at least treat their patients' symptoms with medication or other interventions. ALS caregivers must be more flexible and creative in their attempts to help the patient, but due to the constant changing nature of the disease those interventions may not be effective consistently. Caregivers of ALS patients may rely more heavily than other caregivers on denial as a coping mechanism, to maintain hope and prevent despair (Mitsumoto & Munsat, 2001).

Effects of caring for ALS patients, as compared to other populations, are not necessarily all negative. Because there is often not a great deal outside of the patient-caregiver relationship (and the family) to focus on (i.e., medical advances, treatment options, rehabilitation), the patient-caregiver relationship may strengthen. Faced with the inevitability of death may allow for less important considerations to fall to the wayside and more important aspects of life, love, and relationship to become the (appropriate) focus (Mitsumoto & Munsat, 2001). Although research in general regarding ALS caregivers is limited, in one study, Wooley and Ringel (1997) evaluated more than 800 primary caregivers longitudinally for quality of life. ALS caregiver scores on both mental and physical well-being were found to be close to those reported by the general population.

As discussed, related to ALS patient research, Rabkin and colleagues (2000) investigated the prevalence of depressive symptoms and their correlates in ALS patients and their caregivers, as well as resilience, to identify dimensions of each for use in intervention. A total of 25 caregivers (all but one were spouses) participated in the study, completing self-report forms related to depression, psychopathology, hopelessness, caregiving burden, quality of life, spirituality, and fatigue. Within this sample, 6 percent of caregivers were clinically depressed (similar to the 7 percent of patients), while 21 percent of caregivers displayed moderate depression according to two scales (the Beck Depression Inventory and the Beck Hopelessness Scale) (Rabkin et al., 2000). In addition, higher scores on measure of caregiver burden were significantly correlated with symptoms of depression, lower quality of life, lower scores related to religious beliefs, and fatigue. Unfortunately, those caregivers most significantly (clinically) depressed were also the ones who indicated they must maintain full care of their spouses (indicating they would not be able to ascertain necessary psychiatric services) (Rabkin et al., 2000). Finally, an important finding indicating adaptiveness among this caregiving population, results yielded a positive association between finding meaning in caregiving and perceived caregiver burden (Rabkin et al., 2000).

Contradictory to the findings by Rabkin and colleagues (2000), were those of Neudert, Oliver, and colleagues (2001) related to frequency of clinical depression in caregivers of ALS patients, derived as part of a larger study investigating attitudes toward physician-assisted suicide. According to these researchers, 24 percent of caregivers (22 out of the 91 participants) were clinically depressed (as assessed by clinical interview) (Neudert, Oliver et al., 2001).

Issues Specific to Caregiving Spouses

Most of the literature reviewed has included a large proportion of spousal caregivers, but not necessarily exclusively. As Pearlin and colleagues emphasize, caregiving — activities and experiences related to providing help or assistance to loved ones and friends — exists in most relationships and within established roles (i.e., parent-child or between spouses). These duties become a possible source of stress when the nature of the caregiving becomes unequal and unidirectional, or when the established relationship itself changes because of this increased dependency of the other partner (Pearlin et al., 1990). Caregiving, which previously may have been a subtle component of the overall relationship, has now become the dominant component and may "expand to the point where it occupies virtually the entirety of the relationship" (Pearlin et al., 1990, p. 583). This is especially important with regards to the marital relationship and to spousal caregivers—the population of interest to this investigation.

Role adjustment. It is inevitable that the role of the spouse of a chronically ill patient will be significantly altered as a result of that illness. Whether that spouse becomes the informal caregiver or not, the nature of chronic illness and its demands on those experiencing it (patient or loved one) warrants an adjustment in each member's role, even if only related to level of household responsibilities, for example. But when the spouse of a chronically ill patient becomes the caregiver, the role shifts more drastically from solely "spouse," to now include the provision of life sustaining needs for the patient (related to medical regimen, eating and nutrition, and hygiene), assumption of greater (if not complete) proportion of household responsibilities, and possibly responsibility for financial resources (Ben-Zur et al., 2000; Pearlin et al., 1990). Neudert, Oliver and colleagues (2001) found that 37 percent of caregivers of ALS patients in their study reported a loss of income, 16 percent had to quit work to provide care. The spouse must provide tangible support in addition to the emotional support offered as a loved one. The scope and difficulty of caregiver duties usually requires a sacrifice of previous activities to assume this necessary role effectively. This may be especially true as the illness progresses, limiting social or recreational life for the caregiver (Pearlin et al., 1990). In Neudert, Oliver and colleagues's (2001) study of ALS caregivers, 23 percent reported their social lives suffered frequently, while 22 percent indicated they did not have enough time for themselves. This sacrifice may result in caregivers losing some part of themselves (as they were prior to being a "caregiver"). This loss, in addition to the demands of the new role, may be a significant source of stress. In addition, the "loss of self" was a theme that emerged in an exploratory study (and then was tested and incorporated into a comprehensive scale to assess caregiver variables) of caregivers, and relates to the "extent that the identity and life of the caregiver has been closely bound to that of the patient, the caregiver may experience a loss of his or her own identity as the patient's persona becomes fragmented and blurred" (Pearlin et al., 1990, p. 589).

Relationship adjustment. The marital relationship is a cherished one, and the sudden, "dramatic, and involuntary transformation of (it) is itself a major source of stress" (Pearlin et al., 1990, p. 584). Due to the nature of the chronic illness and the demands on the caregiver, the caregiver-patient relationship is unavoidably restructured, with its former degree of equality lost (Pearlin et al., 1990). If the illness requirements worsen and place greater demands on the caregiver, he or she may "increasingly feel separated from the parts of their lives that have been supported by or shared with their (spouses)" (Pearlin et al., 1990, p. 587) because that spouse's (the patient's) role has also changed. Although it is undeniable that the role of each spouse within the relationship will change, and a great deal of the literature has focused on the negative impacts of the illness on these role changes, as discussed above in reviewing Schulz and colleagues (1990) summation of the literature, it is possible that one or both spouses (and the relationship itself) may experience benefits of the caregiving experience. Important aspects of the relationship, specifically, perceived support, may contribute to the overall adjustment caregivers make and whether that adjustment is a positive or negative one. Although the importance of relationship satisfaction is reviewed later, one study that investigated the impact of spousal support on the caregiver's experience is of importance here.

Dorfman and her colleagues (1996) conducted a study related to investigating satisfaction and strain in caregiving with a group of 80 elderly female caregivers and their frail veteran husbands. They reiterated the lack of literature focusing on caregiver satisfaction — and emphasis, instead, on strain — and note that satisfaction derived from caregiving may relate to the assistance provided to the patient, the sense of efficacy in meeting a significant challenge, or gaining recognition from others (Dorfman et al., 1996). In addition, they summarized findings related to the importance of quality of the marital relationship, perceived support, and closeness between spouses as the strongest predictors of caregiving satisfaction — emphasizing that, although social support has been strongly maintained as a mediator of the strain experienced by caregivers, the possibility of spousal-patient as a source of that support has been often overlooked (Dorfman et al., 1996). These researchers, therefore, predicted that the perceived support from spousal-patient would positively relate to caregiver satisfaction and negatively relate to caregiver strain. Their predictions were supported by the data in a multiple regression analysis: perceived support from the spousal-patient was the strongest positive predictor of satisfaction in caregiving ($B = 0.39$, $p < 0.001$, $R^2 = 23$ percent), and strongest negative predictor of caregiver strain ($B = -0.27$, $p < .05$, $R^2 = 26$ percent) (Dorfman et al., 1996). In fact, "support from spouse was the strongest and most consistent predictor of satisfaction and strain in the study" (Dorfman et al., 1996, p.52). It was also a strong predictor of life satisfaction among the caregivers, but not significantly so when other factors were considered as well.

Dorfman and colleagues (1996) also studied self-efficacy as a mediator for the stressors of caregiving. As this is an important construct in caregiving, and one that has received significant attention in the literature, those findings are reviewed now in a more comprehensive look at the impact of caregiving competency (self-efficacy) on the caregiving experience; and as is under investigation here, as a factor that may predict patient QOL. As all of the reviewed psychological and psychosocial experiences facing caregivers contribute to the overall satisfaction with life and status of well-being, the importance of identifying the impact of caregiving on the caregiver's psychological and psychosocial experiences relates to the construct of QOL. How these factors then influence other aspects of the caregiver's sense of self, interactions with the patient, and possibly the patient's QOL are of primary interest here.

Caregiver Perceived Competence and Self-Efficacy

One such caregiver experience that may impact the patient (and is hypothesized in this investigation) is his or her self-assessed level of competence. As components of their studies, several researchers reviewed in relation to topics already presented also investigated perceived competency, or self-efficacy, in relation to its mediating effects on caregiver satisfaction and strain. Self-efficacy for caregivers relates to their personal assessment that they will be able to manage the role and duties of caregiving. Bandura (1982) explained the benefits of perceived ability to manage stressful situations to include lower emotional distress, completion of the task(s) at hand, and the ability to persist in facing the stressors/obstacles for longer periods of time. Research has supported this construct of self-efficacy as described by Bandura, and has found that higher self-efficacy (perceived competence) does relate to increased caregiver satisfaction, while a lack of self-efficacy contributes to caregiver strain and depression (Dorfman et al., 1996; Haley, Levine, Brown, & Bartolucci, 1987; McClenahan & Weinman, 1998; and Pearlin et al., 1990; Stebbins & Pakenham, 2001).

Dorfman and her colleagues (1996) investigated the effect of self-efficacy, as measured by confidence in ability to manage caregiving tasks derived from Haley and colleagues' (1987) work, on caregiver satisfaction, life satisfaction (often used synonymously with QOL in the literature), and caregiver strain. As predicted, self-efficacy was positively and strongly correlated with caregiving satisfaction ($r = 0.41$, $p < 0.001$) and life satisfaction ($r = 0.42$, $p < 0.001$), while negatively related to strain ($r = -0.29$, $p < 0.01$), indicating its importance in general well-being for caregivers (Dorfman et al., 1996). The relevance in this present investigation is whether or not caregiver self-efficacy also positively relates to the quality of life of the patients they care for.

Stebbins and Pakenham (2001), in investigating the relationship between irrational beliefs and psychological distress in caregivers of traumatic brain injury patients, reported a summation of studies that concluded caregivers' perception of their situation was "more predictive of adjustment than independent, objective measures of caregiving characteristics" (p. 178). In other words, the caregivers' perceptions of their caregiving situations is more influential in determining how they adjust psychologically to their role as caregivers. If they perceive themselves as incompetent to handle the stressors of their role, then they will likely adjust more poorly than those who believe themselves to be more competent, because "their subjective perception of the situation dictates the emotional and behavioral responses" (Stebbins & Pakenham, 2001, p. 180). The emotional distress they experience, as a result of their feelings of inadequacy and incompetence, may unconsciously be communicated to their patients via emotional convergence, potentially negatively impacting, then, the patient's QOL.

Pearlin and colleagues (1990), in developing a conceptual framework for assessing numerous caregiving variables that dynamically contribute to caregiver stress, identified competence as a source of potential intrapsychic strain for caregivers. Actually, their emphasis was on this variable as a potential mediator for caregiver strain, in that caregivers with a higher degree of competence are more likely to experience lower distress in facing the caregiving role. This construct of competence (for which measurement was developed in the article under review) stems from the broader concept of mastery, or "the control that individuals feel they are able to exercise over forces importantly affecting their lives" (Pearlin et al., 1990, p. 589), but more narrowly focused here for use specifically related to the role of caregiving. The questionnaire they developed to assess this construct is used in this investigation.

To this suggestion of the importance of caregiver self-evaluation, Grant and colleagues (2001) contribute that caregivers who are effective problem-solvers (self-evaluated) have a high degree of confidence in their ability to cope with and manage obstacles and regulate their reactions to stress better (including affective, behavioral, and cognitive). If a higher level of confidence in their ability to manage problems is associated with the ability to regulate emotional reactions (for example), then perhaps those caregivers who perceive themselves as more competent would be less likely to allow affective responses to their caregiver duties to be communicated improperly (and detrimentally) to patients and would be less likely to engage in emotional convergence.

In a recent study involving 75 caregivers of ALS patients, Murphy (2002) investigated how caregivers' relationship satisfaction, problem-solving skills, spirituality, and religiosity impact their own QOL and psychological morbidity. Findings indicated that both social problem-solving abilities and spirituality predicted caregiver QOL (Adjusted $R^2 = 15.6$ percent and 7.8 percent, respectively) [$F(2,69) = 11.83$, $p < .001$]. Although this population of caregivers was a relatively psychologically healthy sample, the variance that existed in psychological morbidity was partially explained by social problem-solving abilities (25.4 percent) [$F(1,71) = 25.571$, $p < .001$] (Murphy, 2002).

This study suggests that internal factors may protect caregivers from the deleterious impact that caregiving for chronically ill patients may otherwise present. Specifically, that if caregivers possess strong social problem-solving abilities and rely on their sense of spirituality they will experience a higher rating of overall QOL. Of interest to this present investigation, the level of care provided to the patient was not a significant predictor of either QOL or psychological morbidity in the caregivers. This finding is consistent with Rabkin and colleagues (2000), and further supports that internal caregiver factors are better determinants for their psychological functioning and QOL than patient characteristics.

Although Murphy (2002) acknowledges that her findings related to the lack of predictive ability of relationship satisfaction on caregiver QOL and psychological morbidity is inconsistent with other findings in caregiver literature, this may be due to several factors. Namely, findings may have been limited by the use of a single-item to measure relationship satisfaction, and by the use of non spousal caregivers that may have lent heterogeneity to the nature of the patient-caregiver relationship and, perhaps, variability in the importance/influence of satisfaction in the relationship on QOL (Murphy, 2002). Relationship quality between spouses has been found in several studies to have a strong predictive influence on the degree of strain and satisfaction experienced by caregivers of frail elderly veterans (Dorfman et al., 1996), as well as contributing to depression experienced by caregiving wives of dementia patients (Kramer, 1993; Morris, Morris, & Britton, 1988). Although these studies were not conducted on the ALS population, it is possible that relationship satisfaction would be a similar mediator in caregivers of ALS patients' psychological and psychosocial functioning.

Caregiver Impact on Patient

Emotional Convergence. Although the impact of one spouse's distress on the other is not well researched to date, the literature does suggest that members of a couple experience stressful life events similarly (Goodman & Shippy, 2002; Tower & Kasl, 1995). The literature has also begun to explore the impact of chronic illness — an event experienced by both spouses of a couple because typically caregivers of the chronically ill are the spouses — on the marital relationship; however, findings tend to highlight the negative impact (Goodman & Shippy, 2002). In fact, although some marriages faced with chronic illness do not survive the stressors and strain inherent in the illness process, most do (Cutrona, 1996). The reciprocal and interdependent nature of marriage means that what affects one spouse will affect the other. In other words, the thoughts, feelings, and behaviors of one spouse are strongly influenced by the other (Goodman & Shippy, 2002; Cutrona, 1996). This process has been referred to as emotional contagion or convergence.

Definition. Emotional convergence, as defined here, is similar to emotional contagion, affective contagion, affective convergence, and mood convergence in the literature — the process by which people in close proximity may transfer their mood to others (Bookwala & Schulz, 1996), "catch" or become "infected by" the emotions of others (Hatfield, Cacioppo, & Rapson, 1994; Sullins, 1991; Wild, Erb, & Bartels, 2001) or develop emotional similarity (Anderson, 2001). The focus of this concept is on the proven potential of one person to influence the mood of another. In an investigation to study the effects of one person's depressive symptoms on another person, Coyne (1976) first demonstrated this phenomenon experimentally, in that subjects experienced similarly negative affected responses (depression, anxiety, and hostility) following their conversation with the depressed person. Emotional convergence is especially relevant when talking about the spousal patient-caregiver relationship because both partners are experiencing a significant, emotionally laden life event together. Although discussed in findings above, and studies evidencing the possibility of this phenomenon were mentioned briefly, emotional convergence is especially relevant to the current investigation and warrants a more detailed presentation.

Emotions are responses to environmental changes, providing individuals with a source of orientation and direction in relating to the world and to others (Anderson, 2001). By this definition, it would sound as though emotions are essential in the process of adaptation. This investigation supposes the same, as emotional functioning relates to psychological functioning and overall QOL. If emotions are necessary for successful adaptation, then being able to perceive, interpret, and adopt the emotional states of others may be beneficial in the presence of stressful or threatening stimuli, such as a terminal illness. The literature has hypothesized that the functionality of emotional convergence not only relates to adaptation and survival, but also to effective social functioning, as individuals will collaborate their actions if experiencing similar emotional reactions (Anderson, 2001; Hatfield et al., 1994; Keltner & Kring, 1998).

Functionality. According to Anderson (2001), theorists have traditionally cited three reasons to support this assertion: 1) emotional similarity synchronizes the attention, thoughts, and behaviors of people and facilitates collective, coordinated action; 2) experiencing similar emotions allows people to understand one another better in terms of the other's intentions, motivations, and perspective; and, 3) emotional similarity allows individuals to feel understood and validated, increasing a sense of cohesion and intimacy (Anderson, 2001). As Anderson summarized: "emotions coordinate cognitive and behavioral processes across individuals just as they coordinate cognitive and behavioral processes within individuals" (2001, p. 3). Therefore, a couple who are emotionally similar would be coordinated in their thinking, attention, efforts, and action (Hatfield et al., 1994), feel validated, experience a sense of solidarity, and understand one another (Anderson, 2001). In the case of an ALS patient and his or her caregiver, this emotional similarity would benefit the dyad's overall management of the illness, its symptoms, and the adjustment to changes produced by the illness.

Another possible function of emotional convergence relates to social comparison theory, proposed by Festinger (1954), that asserts individuals have the natural tendency to evaluate their own reactions in stress-producing situations by comparing them to the reactions of others in order to evaluate the accuracy and efficacy of their abilities and opinions. The major postulate of social comparison theory contends that in the absence of objective means to evaluate one's own performance (and the appropriateness of it given the situation), individuals rely on social reality — the behaviors and statements of others in a similar (or same) situation (Festinger, 1954; Wrightsman, 1960). Individuals, according to Festinger, experience pressures toward uniformity in order to reduce the discrepancy between their opinions and abilities and those of the observed others, or to identify their own standing when the situation is ambiguous. These pressures, then, result in the observers altering their opinions and evaluation of their abilities or attempting to alter those of the other person. Wrightsman (1960) and Schachter (as cited in Wrightsman, 1960) extended the reach of this innate drive to include the evaluation of one's emotions by evaluating the emotions of others.

Festinger's social comparison theory is relevant to this investigation because it is possible that, when faced with adapting to the (ambiguous) experience of chronic illness, ALS patients may attempt to ensure the accuracy of their responses and decrease the discrepancy between their responses and the responses of their caregivers by adopting the opinions (or attitudes) and emotions of their caregivers. Social comparison theory offers the motivation for why one partner would attend to the other's emotional status — because of the innate tendency to evaluate one's own performance. Festinger specified this tendency toward uniformity as existing only when individuals have similar others to compare themselves with; that people tend not to compare themselves with divergents (1954). Caregivers of ALS patients are "similar others" to patients, in that they are experiencing and adjusting to the same ambiguous process of a life-threatening illness. In addition, this model explains emotional convergence to the degree that it relieves distress that may result when people in similar situations are not responding similarly. But do individuals always consciously compare their functioning with others and seek to make their emotional responses similar to the emotional responses of others? Or does emotional convergence occur automatically, without one's conscious awareness or effort to adjust his or her emotional state?

Mechanism. Although an exact mechanism to explain emotional convergence is difficult to identify, the literature supports its occurrence. There are different theories that suggest the nature of this process, from those emphasizing empathy as a crucial element (Levenson & Ruef, 1992) to those emphasizing the role of facial expressions and nonverbal "gesture" as either conditioning stimuli that produce conditioned responses (Marañon, 1950), or stimuli that initiate a chain of physiological processes from perception to activation of mood in the receiver (Hatfield, Cacioppo, & Rapson, 1992; Hatfield et al., 1994; Neumann & Strack, 2000; Wild et al., 2001). The consensus seems to indicate that emotional convergence is the result of perceiving the emotional state of another followed by physiological responses in the observer that produce a similar or complementary emotional state. The concept of empathy, for example, as an explanation for the feelings of one person being shared by another also includes the importance of physiology, specifically, shared physiology. Empathy, according to Levenson and Ruef (1992), is a physiological process whereby an observer of another's emotion experiences autonomic arousal and, subsequently, similar emotion.

This notion of a multi step process is similar to the explanation offered by Hatfield and colleagues (1994), who hypothesize that emotional contagion is a "multilevel phenomenon, (whereby) the precipitating stimuli arise from one individual, act upon ... one or more others, and yield corresponding or complementary emotions" in the observer(s) (p. 5). These authors propose the existence of primitive emotional contagion, a mechanism that is "automatic, unintentional, uncontrollable, and largely inaccessible to conversant awareness"(Hatfield et al., 1994, p. 5); and that is the tendency to imitate and synchronize the movements, postures, verbalizations, and expressions of another, and produces emotional convergence (Hatfield et al., 1992). Hatfield et al. (1994) proposed that when interacting with others, people "automatically and continuously mimic and synchronize their movements with the facial expressions, voices, postures, movements, and instrumental behaviors of others" (p. 10). This mimicry produces feedback on a moment-to-moment basis that affects the observer's subjective emotional experiences. This feedback process is guided and/or influenced by three possible means: 1) the direction of the central nervous system that initiated the synchrony; 2) the afferent feedback from the mimicked movements, postures, facial or verbal expressions; or 3) "self-perception processes wherein individuals draw inferences about their own emotional states based on the emotional expressions and behaviors evoked in them by the emotional states of others" (Hatfield et al., 1994, p. 10-11).

In support of their theory, Hatfield and colleagues (1994) presented relevant research findings related to the tendency of individuals to mimic the facial and vocal expressions, postures, and movements of others, as well as to the process of feedback activated in the observer that results in the similar or complimentary emotional experience. These authors referenced studies that proved, through the use of EMG and other physiological means, that faces not only mirror the emotional expressions of others, but that they can also detect and follow the moment-to-moment changes in the other person's expression and mimic those changes instantaneously (Hatfield et al., 1994). In addition, research findings suggest that humans are pre wired with an innate mechanism for autonomic nervous system responses to emotional faces, as is evident in newborns and lab research with isolated animals that do not "learn" these responses (Hatfield et al., 1994). In one particular review summarized by these authors, it was reported that individuals are capable of imitating others' expressions of pain, affection, smiling, laughter, embarrassment, stuttering, discomfort, and disgust, and that this imitation is an act of communication to convey information nonverbally, rapidly, and precisely (Hatfield et al., 1994). In sum, Hatfield and colleagues (1994, p.5) propose that people tend to mimic or synchronize with the facial and vocal expressions, postures, and movements of others around them automatically, and then "experience emotions consistent with the facial, vocal, and postural expressions they adopt."

With regard to findings that support the existence of a feedback mechanism, Hatfield and colleagues (1994) summarized a great deal of literature that supports the assertion that emotions are influenced at least somewhat by facial muscle, vocal, and postural feedback and muscle movement feedback. (For a full review see Hatfield et al., 1994.)

Following the work and theory of Hatfield and colleagues (1992, 1994), Wild et al., (2001) summarize emotional convergence as having three components: the perception of others' facial expressions that triggers facial imitation, activation of facial receptors that communicate the experience of a given emotion, and the evocation of emotions in the observer to be congruent with the physiological experience. Research findings in the emotional convergence literature have reported that facial movements can induce emotions, and that, specifically, "experimental manipulation of facial activity can produce specific changes in corresponding emotional feelings" (Wild et al., 2001, p. 111). These findings included the emotions of anger, sadness, fear, happiness, and disgust (Wild et al., 2001), as well as anxiety, aggression, sadness, and fatigue (Sullins, 1991). The emotion induced does not always equate completely with the emotion being expressed, but is typically either similar or complimentary in nature (i.e., smiles eliciting smiles, disgust and fear as a reaction to anger, disgust in reaction to fearful facial expressions) (Hatfield et al., 1994; Wild et al., 2001). This theory of emotional convergence, as described and supported, is relevant to the present investigation in that it implies that even subtle, moment-to-moment affective changes in one person may produce the same, similar, or complimentary emotional changes in another person in close proximity. For spousal patients and caregivers interacting so frequently, regularly, and intimately, the reciprocal influencing of each other is inevitable.

Factors. In addition to explaining the mechanisms that produce emotional convergence, the research has highlighted factors that facilitate this process and strengthen the likelihood that it will happen. Some theorists propose that the effectiveness of one person influencing the emotional experience of another depends on individual characteristics of either person. For example, a person influencing another is more likely to be nonverbally expressive while the person being influenced is less nonverbally expressive (Friedman & Riggio, 1981; Sullins, 1991). As mentioned previously, degree of relevance is important in whether or not emotional convergence will occur (i.e., similarity in circumstance) (Festinger, 1954), as was found by Sullins (1991) when greater emotional convergence was noted between participants waiting for the same experimental event than those waiting together for different experiences.

With regard to gender differences, a great deal of the literature discusses the possibility that women may be more susceptible to emotional convergence than men because they are stronger facial-expression imitators (Hatfield et al., 1992, 1994). (For a full review of the literature on gender differences, see Kring & Gordon, 1998.) Although Kring and Gordon's (1998) findings supported those of other studies with regard to women being more facially expressive, their findings did not support that women are more susceptible to experienced emotion. According to Wild and colleagues (2001), most studies that report gender differences in emotional experiences do not use stimuli of facial expressions to elicit emotional responses, and only one study has directly assessed gender differences in emotional contagion. As the majority of ALS patients are male and the majority of caregivers are their female spouses, the finding that women are more facially expressive may have implications for the susceptibility of the patients to the emotional convergence process.

Anderson (2001), in investigating whether or not emotional convergence is more the result of one person's influence or an "averaging" of each individual's emotional state, found that the partner with greater "power" influenced the less powerful partner more than vice-versa: the Time 1 emotions of more powerful partners were significantly better predictors of Time 2 emotions of less powerful partners (Total emotion: $r = .69$, $p < .01$; Positive emotion: $r = .50$, $p < .01$; Negative emotion: $r = .53$, $p < .01$) than vice-versa (Anderson, 2001). His review of the literature related to the influence of power in relationships indicates that those "with less power attend to those with high power more than vice-versa," and that "people with lower power mimic the behavior of people with high power" (Anderson, 2001, p. 10). This particular finding is especially relevant to the current investigation examining emotional convergence within a spousal patient-caregiver dyad. As ALS patients become dependent on caregivers for daily living tasks and basic needs, caregivers are potentially the more "powerful" partner in the relationship.

In addition to characteristics of the people involved in the emotional exchange, the nature of the mood state itself has been found to be important in whether or not contagion occurs. Negative moods, such as anger, anxiety, and aggression, have been found to be more likely than positive moods, such as happiness, to be "contagious" (Friedman & Riggio, 1981; Sullins, 1991), even when subjects were under the influence of drugs to produce emotional states (Nowlis & Nowlis, 1956).

To summarize the review of the literature related to emotions, it would appear that humans are innately "hard-wired" for spontaneous, automatic communication of emotion, whether expressing feelings overtly through facial displays and gestures or quickly detecting the emotions of others through the same channels (Anderson, 2001). It also appears that there is a natural drive to ensure accuracy and efficacy of functioning. Within the social context (i.e., spousal relationships), this produces a desire and effort to coordinate responses and resources for the most productive, accurate, and directed approach to managing difficult situations. Hatfield and colleagues' (1994) explanation for this mechanism, as well as Festinger's (1954) social comparison theory and Anderson's (2001) summary of the functionality of emotional convergence, will be the most relevant when pursuing the following investigation of caregiver variables as they may influence the emotional and psychological functioning of ALS patients; namely, their overall QOL.

Supportive Research. As is of specific relevance to this investigation, other studies have explored the phenomenon of emotional convergence as it occurs in spousal dyads. As summarized by Bookwala and Schulz (1996), the effects of emotional convergence are stronger and more probable when people feel responsible or care for others, identify with them, or pay attention to them. This suggestion is central to the question under investigation here, in that caregivers' perceptions of the relationship and their own competence, and specifically the affective responses those perceptions produce, may be more likely to influence their patients' QOL given the nature of the caregiver-patient relationship.

Gaelick and colleagues (1985) investigated emotional communication within intimate relationships, specifically assessing reciprocity of emotion. With regards to the emotions of both love and hostility, they found that (a) individuals believed that their partners were mirroring their emotion, and (b) they reciprocated the emotion that they perceived their partner to be communicating. These findings are consistent with the theory presented by Hatfield and colleagues (1994), outlined above. The implication for the research in the present study is significant: if caregivers are experiencing dissatisfaction in the intimate relationship with the patient, then the patient will likely mirror that same emotion, as could be measured in a lower subjective rating of QOL (if it includes items measuring relationship satisfaction). Similarly, if caregivers do not perceive themselves as competent and exhibit a downtrodden, helpless, or depressed affective response to that belief, then patients may "adopt" the same emotional disposition feeling equally helpless or depressed (as would, again, be evidenced in a lower subjective evaluation of QOL). It is possible that the negative affect or incompetence that caregivers may feel (that is impacting patients) actually originates from the patient's depression and ultimately leads to further reinforce the patient's depression. This additional example of emotional convergence evidences the importance of the cyclical nature of emotion in close relationships.

Similar to the effects of emotional convergence, Bookwala and Schulz (1996) investigated the extent to which one spouse's subjective well-being can be predicted by that of the other. There were 1,040 spousal pairs of community dwelling, age 65 and older adults who were participants of the larger Cardiovascular Health Study and were not involved in hospice and did not have a terminal illness. Participants were given a structured interview that included assessing sociodemographic variables, medical history, physical functioning, psychosocial status, physical activity, and well-being (via four indices). After controlling for sociodemographic variables and health states, the authors found that a spouse's well-being was significantly predicted by the well-being of his or her partner (Bookwala & Schulz, 1996). In addition to their findings, these authors reviewed multiple other studies in the literature that reported the phenomenon of emotional convergence as frequently observed in spousal and significant-other dyads.

In their study of 317 married, community dwelling senior couples, Tower and Kasl (1995) found that one spouse's level of depressive symptoms influenced the level of the other spouse, independent of the subject's age, race, education level, financial status, and status on several health or physical conditions and independent of his or her spouse's health status. In addition, they found this was true more often when couples were close than when they were not close. These investigators suggested that emotional convergence could be the mechanism that resulted in these findings, given the moderating factor of closeness (Tower & Kasl, 1995). They examined the influence of one spouse's emotional status on the status of the other spouse longitudinally, and found that a change in the depression level of one spouse significantly predicted the depressive symptoms of the other (Tower & Kasl, 1996).

Although there is little research specifically investigating the presence of emotional convergence between spousal patient-caregiver dyads, in one study researchers investigated emotional convergence of depressive symptoms in the context of age-related disability. In a sample of 123 older adults with vision loss and their spousal caregivers, Goodman and Shippy (2002) found that "elder depression uniquely contributed to the prediction of spouse depression, which is evidence of emotional contagion" (p. 272). Specifically, in the final step of hierarchical regression analyses, spousal-patient depressive symptoms explained an additional 2% of the variance in caregiver-spousal depression [$F(10,119) = 18.04$, $p < .05$). Despite these findings, limitations of this study relate to a small sample size, recent onset of disability, and the notion that emotional similarity between spouses is variable and may change throughout the adaptation to disability.

In Rabkin and colleagues' (2000) research investigating (among other things) the relationship between ALS patient and caregiver distress levels, despite a small sample size ($N = 21$) the concordance was high (ranging from 0.55 to 0.72) on measures of anxiety, depressive symptoms, and quality of life. As these researchers concluded, "this reflects findings in other studies … and suggests that attention to the mental health needs of the caregivers may not only relieve their own depression but may alleviate the patient's distress as well" (Rabkin et al., 2000, p. 277). This is the nature of the present investigation, given these findings within the patient-caregiver population (although few in number) and the empirically supported theoretical models of emotional convergence and social comparison theory outlined above.

Caregiver Relationship Satisfaction

As was also noted previously, relationship quality between spouses has been found to be a strong predictor of the level of strain and satisfaction experienced by caregivers, as was the amount of perceived support caregivers received from their spousal-patients (Dorfman et al., 1996). In addition, a poor quality relationship and lack of intimacy between spouses has contributed to caregiving wives' depression and experienced strain (Kramer, 1993; Morris et al., 1988). It is speculated here that the same factors may be influential in the degree to which patients experience their illness negatively or adjust to it. In other words, their psychological well-being when facing chronic illness or their QOL.

One study specifically attempted to investigate how caregiver affect and relationship satisfaction impacts patient functioning, similar to the aim of this study. In investigating relationship satisfaction as related to spousal negative responses to cancer patients, Manne and colleagues (1999) surveyed 219 cancer patients and their healthy spouses. Caregivers completed the Dyadic Adjustment Scale (DAS) 3 months before to the other measures in an attempt to establish a more accurate assessment of marital satisfaction prior to illness onset than retrospective ratings would provide. This also offered "the advantage of assessing marital quality at an earlier and different point in time than perceived spousal negative behaviors and spousal mood" (Manne et al., 1999, p. 354), as was being assessed for the investigation. This does not, however, guarantee that caregiver ratings 3 months prior than others were not also influenced negatively by negative variables or that perception of relationship satisfaction hadn't changed. The majority of measures were then collected, and included a medical history, caregivers' measure of negative mood (six mood descriptors from the NA scale of the Positive and Negative Affect Schedule indicating distress and irritation), and degree to which the patients' disease and treatment interfered with their own social and recreational activities (Impact of Caregiving Scale). Patients completed measures of functional impairment (the Physical Functioning subscale of the Cancer Rehabilitation and Evaluation System) and perceived spousal negative behaviors (a scale developed by one of the authors, Manne, 1997).

Findings supported the researchers' hypotheses: for those caregivers who indicated satisfying relationships prior to completing other measures, limitations in personal time were not significantly associated with emotional distress, and emotional distress was not significantly associated with critical responses to the patient; whereas, for those caregivers who indicated a less satisfying relationship, each of these associations were significant (Manne et al., 1999). Because unhelpful and critical actions can have a significantly negative effect on the well-being of patients (Manne et al., 1997), the findings in this study that patients' perceptions of these behaviors are associated with a lower level of relationship satisfaction of the caregiver suggests that there is a predictive link between caregiver relationship satisfaction and patient quality of life (that if dissatisfied with the relationship, caregivers may present negative interactions to the patient that decrease the well-being of the patient, or, his or her QOL).

One possible limitation in this study is the finding that among caregiving spouses who were satisfied with their relationship, patient decline in functioning was directly associated with both negative affect of the caregiver and perceived negative actions; however, this was not due to the increase in limitations placed on the caregiver by the decreased patient functioning (Manne et al., 1999). One possible explanation is that the progression of the illness elicited other emotional and cognitive responses and distress for the caregiver than were examined in the study. An additional limitation of the findings of this investigation involves sampling, specifically selection bias, in that a large proportion of patient-caregiver dyads recruited for participation did not participate (47 percent) (Manne et al., 1999). The researchers presented information they had obtained on those who declined to participate. Nonparticipants were more ill and had lower relationship satisfaction, which makes them an unrepresentative sample of the target population. In addition, the relationship satisfaction scores (Mdn = 123, M = 120) for those who did participate were significantly higher than the norms for married couples (the typical cutoff point of 100) (Manne et al., 1999). Another potential limitation of this study relates to the use of the Perceived Negative Spousal Behavior measure developed by the first author, Manne, originally in 1990 for use with rheumatoid arthritis patients and adapted in 1997 for use with cancer patients (and reused in this study under review). Although the authors indicate that principle component analysis was conducted on the original 13-item measure and two factors accounted for the majority of items (11) (Manne et al., 1997), no statistical information was provided, therefore making validity of this measure uncertain. The authors indicated that internal consistency was established, using coefficient alpha, for their two subscales as .77 and .82.

Of final note regarding this article, and significant interest to this study, is the summation Manne and her colleagues (1999) made of the literature regarding caregiver assessment of preillness relationship: that those individuals indicating a close, satisfying relationship report less burden, regardless of level of care. This is consistent with the research presented previously (Dorfman et al., 1996; Haley et al., 1987; Kramer, 1993). These findings, including Manne and colleagues (1999), may each be limited by the accuracy of attempts to elicit preillness attitudes retrospectively. Finally, and to offer support for the indication that characteristics of the caregivers' relationships with their patients influence the caregiving experience, Williamson and Schulz (1990) presented findings that a lower level of caregiver affection for the patient may result in increased resentment regarding the sacrifices necessary to provide care. These findings together — that higher caregiver level of satisfaction in the intimate relationship with the patient allows for less negative affect for the caregiver, better response to increased demands of caregiving, and less communication of these negative emotions and beliefs to the patient — suggest a relationship between caregiver experience and the adequacy of the care provided to the patient.

One study explored the ability of significant others to correct for the effects their negative affect may have on subjective evaluation of their relationship satisfaction. Tesser and Beach (1998) investigated the relationship between stressful life events, negative affect, and perceived quality of intimate relationships in patients with depression. Essentially they discovered that negative life stressors exert nonlinear effects on an individual's judgment of his relationship quality with a significant other. Of greatest significance in this study is not simply that persons perceive their relationships negatively when experiencing negative affect in response to stress, but that this evaluation will be modified (corrected for) when people become aware they are doing it. However, when the stress becomes overwhelming again and surpasses the cognitive and affective resources of the individual, he or she will not be able to correct for his or her affective condition and, again, without awareness, perceive the relationship to be less favorable (Tesser & Beach, 1998). This research suggests that subjective appraisal of the relationship may prompt an awareness on the part of the responder that could allow for correction of the effect of stress on that appraisal, even if only temporarily. The implications of this suggestion on intervention with patient-caregiver dyads is significant: intervention by professionals, through support, therapy, and education, would likely prompt more frequent assessment of relationship satisfaction that may, in turn, allow caregivers more frequent opportunities to correct for and reduce the effect that negative life stress would have on the relationship and ultimately the patient's QOL. This possibility is one that may be explored in an intervention study should results from this investigation indicate that a relationship exists between caregiver variables and patient illness experience or QOL.

Quality of Life

Definition. As the field of behavioral medicine has been expanding over the past two decades, a great deal of attention has shifted focus away from the medical treatment of chronically ill patients toward their experiences, namely QOL. Although there is no single agreed upon definition of QOL, and the attempt to even create a broad definition to account for an individual, psychological experience has been criticized, many adequate, functional definitions that allow for measurement have been offered. One such simple proposed definition is "the extent to which our hopes and ambitions are matched by experience" (Mitsumoto & Del Bene, 2000, p. 329). The World Health Organization (WHO) has defined QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO Group, 1998, p. 551). This definition allows for the inclusion of cultural context in one's sense of life satisfaction, in addition to one's goals and expectations for life.

These definitions, as with many that have been offered, emphasize individuals' goals or hopes as important factors and it is the intention to do the same here. Gill and Feinstein (1994) caution readers of QOL literature, especially in studies involving medical populations, that often "quality of life" is substituted "for others terms intended to describe a patient's health, such as 'health status' or 'functional status'" (p. 619). These authors further suggest that true measurements of QOL will include assessment, in addition to physical and health-related factors, of emotional well-being, mental health, functional well-being, job satisfaction, familial relationships, friendships, and other life factors (Gill & Feinstein, 1994).

Another frequent component in defining QOL has been satisfaction with one's main psychosocial life areas (Chibnall & Tait, 1990). Ditto, Druley, Moore, Danks, and Smucker (1996) further suggest that "the very enterprise of QOL measurement is based on the premise that the effects of disease can be understood only by knowing the disease's impact on an individual's ability to function intellectually, physically, and socially" (p. 334), and emphasize the importance of being able to perform "valued life activities" as factors affecting QOL. To that conceptualization, with the intention of consolidating a definition for use with a chronically, terminally ill population, the importance of an individual's ability to function emotionally, as much of the literature discusses the affective impact of chronic illness on patients (Koch, Rumrill, Roessler, & Fitzgerald, 2001; Tesser & Beach, 1998), is included here. For the present purposes it is sufficient to say that QOL is a subjective, variable measure that will be conceptualized here as one's satisfaction with physical, social, emotional, cognitive, and spiritual domains of functioning, on a continuum from completely satisfied (overall) to completely unsatisfied. This definition incorporates the congruence of one's present status with one's goals, expectations, and desires related to important psychosocial life domains.

Measurement of QOL. Hundreds of measures, both general and disease specific, have been developed to assess QOL in a variety of populations (Cohen, Mount, Strobel, & Bui, 1995; Gill & Feinstein, 1994; Gladis, Gosch, Dishuk, & Crits-Christoph, 1999; Pratheepawanit, Salek, & Finlay, 1999). Several have been more frequently represented in the literature (Burckhardt, Woods, Schultz, & Ziebarth, 1989; Cohen et al., 1995; Gill & Feinstein, 1994). The Sickness Impact Profile (SIP) is a widely utilized general measure of QOL and, although the most thoroughly validated measure and often used with medical patients, its lengthiness and generic nature may be insufficient for use with a specific illness population (Mitsumoto & Del Bene, 2000). Gill and Feinstein (1994) compiled a list of QOL measures utilized within medical literature, and identified that the most commonly used, in addition to the SIP, were the Functional Living Index-Cancer (FLIC), Karnofsky Performance Index, and the Bradburn Affect-Balance Scale. Since that investigation, and due to the increasing emphasis in the literature on the construct of QOL, numerous measures have been developed and applied within the medical population.

More recently, and of relevance here, the McGill Quality of Life Questionnaire (MQOL) has been validated for use with patients with HIV, cancer, and other life-threatening illnesses (Cohen et al., 1995; Cohen, Hassan, Lapointe, & Mount, 1996; Cohen, Mount, Tomas, & Mount, 1996; Pratheepawanit, Salek, & Finlay, 1999; Simmons et al., 2000). Some existing measures, and some more recently developed assessment tools specifically for this purpose, have been utilized to assess the QOL of caregivers of chronically ill patients as well, such as the MQOL (Cohen et al, 1995), Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (Bromberg & Forshew, 2002), and the Endicott Quality of Life Enjoyment and Satisfaction Questionnaire (Rabkin et al., 2000).

Research Investigating QOL

Research investigating QOL has provided significant information about the impact of chronic illness on patients, and their caregivers, and has allowed researchers to distinguish between groups of patients, predict patient outcomes, and evaluate therapeutic intervention (Gill & Feinstein, 1994). There is no doubt that the use of measures aimed at assessing QOL will provide useful information and allow for a greater understanding of the experiences of the chronically or terminally ill; and, therefore, an avenue with which to improve the provision of treatment. Despite some valuable findings, QOL research with the medically ill has tended to avoid considering certain important factors, and has relied too heavily on others, limiting the accuracy of this kind of assessment tool.

QOL research in chronically ill patients has tended to focus on how QOL changes during the course of the disease due to progressive loss of control, functional limitations, adaptation to the physiological issues of disease, its progression, and treatment, but assumes that the change is a negative one — that QOL declines simply because the person's health status does (Cohen et al., 1995). The development of the MQOL was based on concern for this overassumption, as well as the tendency for investigators developing QOL measures to overemphasize physical factors. Terminally ill patients, then, would naturally score lower on these measures though they may not have lower levels of QOL (Cohen et al., 1995). As discussed at length previously, there are numerous factors influencing the manifestation of psychological disturbance and maladjustment in those facing chronic and terminal illness. As the presence of distress and difficulty adapting to the reality of one's situation clearly negatively impacts ratings of QOL, those potential mediators are of relevance whenever QOL is under examination. This is the intention of the present investigation, and as numerous examples have been discussed already (in terms of both patient and caregiver well-being), a sampling of some of the identified mediators within the QOL literature will now be exemplified.

In their investigation, Newsome and Schulz (1996) predicted that social support would be a mediating factor between physical functioning and quality of life. Their study examined a national sample of 4,734 adults, age 65 and over, assessed using a variety of self-completed measures for physical functioning and limitations, objectively and subjectively perceived social support, depressive symptomatology, and life satisfaction. Their results indicated that lower self-reported social support (as may be interpreted by the patient if the caregiver is displaying less affection/satisfaction, for example) is an important factor in decreases in QOL. Similarly, life satisfaction was most strongly predicted by perceived support measures, with more perceived support associated with higher satisfaction (Newsome & Schulz, 1996). Limitations in generalizability of these findings to this study relate largely to external validity, as the sample was comprised solely of subjects age 65 and older, who were not ALS patients, nor necessarily patients of a chronic or debilitating disease, and did not necessarily have or require a caregiver. Of additional interest, however, is that these authors also reported, based on their review of numerous studies on social support, that social support has been widely documented to correlate with both depressive symptoms and life satisfaction (Newsome & Schulz, 1996), two key elements (subjective assessment of satisfaction with life domains and affective experience) of QOL. Incidentally, caregivers experiencing decreased social support as a result of increased demands on them as caregivers may be just as likely to experience the same deleterious effects on affect and life (possibly relationship?) satisfaction.

Of importance at this point, are findings by Staniszewska (1999) related to the applicability of QOL measures with ethnic minority groups. In assessing health-related QOL using the SF-36 with 10 (Asian) Indian and 10 (Caucasian) control group patients, Staniszewska found no major differences in perception and interpretation of the SF-36 between the study group of Indian patients and the control group. Minor differences between the groups were also few, but included patient definition of ill-health, whereby Indian patients defined ill-health in terms of mobility and confinement, and Caucasian control patients referred primarily to their inability to do certain tasks. As the SF-36 tends to also emphasize the inability to perform tasks as a key component of ill-health, this may be a source of bias for ethnic minorities and requires further investigation.

Several important points must be noted. First, the lack of significant finding may be more a result of the relatively small sample size than of no difference between majority and minority groups. In addition, the author cautions that the patients comprising the Indian sample were all men, who had lived in Britain for more than 10 years, and were likely acculturated to Western perception of health and illness (Staniszewska, 1999). Second, the measure used assessed only health-related QOL, which may not be comparable to measures of QOL of a broader nature (including the one utilized in this investigation). Third, the study was piloted on a sample of only six Caucasian participants and none of the ethnic group investigated here. For the pilot, as well as the actual study, those participants receiving phone interviews received their SF-36 measures in the mail prior to interview. It is hoped, but a concern nonetheless, that participants would complete these questionnaires without the influence and/or assistance of others. Fourth, data for the study was collected via telephone interview. Although potential bias exists, a benefit of this collection method, given the issue under investigation, is that it may have been able to reduce the participant reaction toward an ethnically different examiner. Regardless of these considerations that may question the findings, Staniszewska (1999) raised an important question related to the measurement of such a subjective construct as QOL: "culture may affect the perception and interpretation of health and illness and so may affect the responses to items in a questionnaire" aiming to measure them (p. 51). This consideration needs to be kept in mind in all studies assessing QOL, and will be discussed with regard to this investigation later.

Measurement of QOL within ALS

Despite the multitude of available measures currently used, more recent emphasis within the ALS literature has been to identify an existing measure (or create one) of QOL that more adequately assesses the unique experiences of these patients and with the specific course of this disease in mind (Bromberg & Forshew, 2002; Clarke et al., 2001; Robbins et al., 2001; Simmons et al., 2000). Because of the unique nature of this illness, and the lack of treatment options or a "cure," QOL becomes an especially important variable to aid in what intervention can be offered for this population. Several researchers have attempted to identify an adequate measure of QOL for persons with ALS.

A version of the SIP was specifically developed for use in the assessment of ALS patients (the SIP/ALS-19) (Clarke et al., 2001; McGuire et al., 1997; Mitsumoto & Del Bene, 2000). In addition, the Short Forms 12 and 36 (SF-12, SF-36) have been used in some clinical trials with this illness (and the ALS CARE database) (Mitsumoto & Del Bene, 2000). However, although these measures aim to be shorter in length for ease of use with ALS patients, like so many others they assess health status but do so with primary emphasis on physical functioning and disease progression (Bromberg & Forshew, 2002; Clarke et al., 2001; Mitsumoto & Del Bene, 2000; Neudert, Wasner, &

Borasio, 2001; Robbins et al., 2001; Simmons et al., 2000). An instrument specific to ALS, the 40-item ALS Assessment Questionnaire (ALSAQ-40), has been utilized to assess QOL with this unique population (Mitsumoto & Del Bene, 2000). This measure assesses functioning in five areas: eating and drinking, communication, activities of daily living and independence, physical mobility and emotional functioning (Clarke et al., 2001). Although internal reliability and construct validity have been reported to be good, this measure was developed as a disease-specific health status measure and appears to do only that — measure nearly entirely physical functioning and disease progression.

Although not specifically developed for the ALS population, more recently the MQOL (Robbins et al., 2001; Simmons et al., 2000) and the Schedule for the Evaluation of Individual Quality of Life Scale (SEIQoL) have been employed with ALS patients to measure QOL (Bromberg & Forshew, 2002; Mitsumoto & Del Bene, 2000). The SEIQoL was developed for use with medical patients, in response to the common assumption of other scales that the same issues apply for all patients, and to allow patients to tell investigators what QOL is for them *individually*. Although weighting of the SEIQoL (the SEIQoL-DW, or Direct Weighting form) allows for comparison of total QOL scores across patients, there is less ability to compare specific domains of QOL because patients assign the five domains in their protocols different personal identities corresponding to important aspects of their lives. Bromberg and Forshew (2002) found a low correlation between scores on the SEIQoL-DW and measures of physical function, indicating that the SEIQoL-DW measures factors other than physical status. In addition, and of interest, these researchers found that ALS patients had higher ratings of QOL, on average, than their spousal caregivers.

The MQOL, like the SEIQoL, relies less heavily on physical functioning and allows for individual patients to dictate certain contributing factors to their QOL (namely, their physical symptoms, as questions related to this domain are open-ended). As described above, the MQOL was developed as a result of existing models overemphasizing physical functioning; however, Cohen and colleagues also conceptualized the MQOL to allow for the contribution of positive life factors to QOL, to include an existential component to QOL (that had otherwise been neglected), and to correct the assumption that QOL consists of specific, universal factors that can be measured (Cohen et al., 1995; Cohen, Hassan, et al., 1996; Cohen, Mount, et al., 1996). Questions are more general to ensure the applicability of each question to each patient. The MQOL is comprised of five submeasures that assess patients' status within five domains: physical symptoms, physical well-being, psychological well-being, existential well-being, and support domains (Cohen, Hassan, et al., 1996; Cohen, Mount, et al., 1996; Pratheepawanit et al., 1999). These subscales may be utilized alone to allow for specific domains to be assessed for each patient, or their means may be averaged for a total QOL score. In addition to the items comprising the MQOL and its submeasures, the first part of the questionnaire is a Single-Item Scale (MSIS) to assess overall QOL and for use in comparing the total MQOL score (Cohen, Hassan, et al., 1996; Cohen, Mount, et al., 1996).

Simmons and colleagues (2000) investigated the appropriateness of using the MQOL with the ALS population while attempting to determine the relationship between physical functioning and QOL and whether religiosity/spirituality is a factor of QOL. It was found that scores on the MQOL correlated highly with the MSIS. The MSIS did not correlate highly with measures of physical functioning, nor with the SIP/ALS-19 that correlated with physical functioning. Other correlations were significant, and overall findings suggest psychological factors, existential factors, and support (as assessed by the MQOL subscales) each play an important role in patients' experience of their QOL, despite their debilitations and limitations. In addition, QOL, as assessed by the patients using the MSIS, was, on average, high (Simmons et al., 2000). These findings may contradict what is often assumed about life-threatening illnesses — that they necessarily reduce the quality of patients' lives (Cohen et al., 1995).

In a follow-up study by the same investigators, Robbins and colleagues (2001) assessed the appropriateness of the MQOL in assessing ALS patient QOL longitudinally and found that this measure did not deteriorate along with physical function, while the SIP/ALS-19 did. This finding lends additional support to the SIP/ALS-19 as a good measure of physical function, and to the MQOL as a measure that more accurately assesses patient experience of QOL over time. As the MQOL has been successfully utilized with ALS patients in the past (Robbins et al., 2001; Simmons et al., 2000), it is hopeful that its use in this investigation will yield reliable, beneficial results.

Hypotheses

This study examines the relationship between caregivers' spousal relationship satisfaction and caregivers' perception of their own competency, and the ways in which these factors impact patients' quality of life. Specifically, this study aims to test the following hypotheses:

(1) Relationship satisfaction, as rated by the spousal caregivers, and how competent caregivers perceive themselves to be in the role of caregiver will predict patients' QOL independent of level of care required by patients and after several varied aspects of QOL (from five domains of functioning, as represented by the total score on the MQOL) are considered.

(2) Relationship satisfaction, as rated by the spousal caregivers, does not relate significantly to how competent caregivers perceive themselves to be.

Chapter 2: Method

The present investigation utilized data collected as part of a larger study of both patients and caregivers separately.

Participants

A total of 177 patients and 75 caregivers chose to participate as part of a larger study while attending a multidisciplinary clinic at a primarily rural university hospital in Pennsylvania. Patients and caregivers recruited for this study represented a convenience sample, and patients were at various stages of ALS disease progression. The primary investigation consisted of two components: one aimed to assess issues related to ALS patients' QOL, while the other investigated the relationships between QOL, psychological morbidity, and religiosity, and problem-solving abilities of the Caregivers of ALS patients. Specific to this exploration, the data consists of 53 ALS patient-caregiver dyads (taken from both components of the larger study) in which the caregiver in each dyad was specifically a spouse or life partner and resided in the home with the patient (the patient did not stay at a nursing care or other facility, but at home and cared for primarily by his or her spouse or life partner).

Inclusion criteria were that each patient was (1) diagnosed with ALS; (2) English speaking; (3) cognitively competent, as assessed by physician, nurse, and the investigators; and (4) able to give informed consent. Inclusion criteria for caregivers were that each caregiver was (1) 18 years of age or older; (2) functioning as the primary caregiver for an individual with definite or probable ALS as diagnosed by the attending neurologist; (3) English speaking; and (4) a spouse or significant other/life partner. The "primary caregiver" was defined as the person who provided the majority of daily care (i.e., greater than five days per week) to the ALS patient. Exclusion criteria for both patients and caregivers were the presence of cognitive impairments, unwillingness or inability to provide informed consent, non-English speaking, or an inability to read English at least at an 8th grade level (as assessed by self-reported education level and comprehension of the consent form, as evaluated by the investigator of each study). While patients were read the assessment measures, reading was required for caregivers completing tools of the study.

Statistical analyses of the demographic data of both caregivers and patients are descriptive in nature and are divided into categorical and scaled data. Categorical data were derived from items on the demographics questionnaire measuring gender of both caregivers and patients and employment status of caregivers; while scaled data were derived from items measuring age of both caregivers and patients, years of education of caregivers, the years of the caregiver-patient relationship (as provided by the caregivers), patients' age at onset of symptoms, and duration of patients' symptoms (see Table 1).

The majority of caregivers in this sample were female (N = 37, 69.8 percent), and the minority male (N = 16, 30.2 percent). This imbalance of gender is reflective of the ALS population, in that the majority of patients are male and the majority of caregivers are their spouses. The average length of the caregiver-patient relationship (in years) was 35 (SD = 16.25), with the lowest number of years being 2 and the most 59.

Table 1

Demographic Information

ALS Caregivers

Variable	Mean	SD	N	%
Age	59.43	13.60		
Education	13.32	2.23		
Years of Relationship	35.00	16.25		
Gender				
Male			16	30.2%
Female			37	69.8%
Race				
Caucasian			51	96.2 %
African American			2	3.8%
Employment Status				
Employed			20	37.7%
Not Employed			13	24.5%
Retired			20	37.7%
Total in sample			53	

ALS Patients

Variable	Mean	SD	N	%
Age	60.48	13.32	53	
Duration of Symptoms (mos.)	28.32	29.84	53	
Gender				
Male			34	64.2%
Female			19	35.8%
Age of Onset				
20-29			1	1.9%
30-39			3	5.6%
40-49			9	17.0%
50-59			15	28.3%
60-69			12	22.7%
70-79			13	24.5%
Total in sample			53	

The average age of caregivers was 59 years (SD = 13.6). The majority of caregivers were Caucasian (N = 51, 96.2 percent,), and minority were African American (N = 2, 3.8 percent). Many caregivers reported working, at least part-time (N = 20, 37.7 percent), while 24.5 percent were not employed (N = 13) and 37.7 percent were retired (N = 20). The average number of years of education caregivers completed was 13.3 (SD = 2.2), with 7.5 percent (N = 4) of caregivers not completing high school, 49.1 percent (N = 26) receiving their high school diploma, 13.2 percent (N = 7) attending at least some college, 24.5 percent (N = 13) receiving a 4-year degree, and 5.7 percent (N = 3) receiving education at the graduate level.

In this sample, 19 patients were female (35.8 percent), 34 were male (64.2 percent). The average age of patients was 60.5 (SD = 13.3), with the youngest being 27 and the oldest 80. The average age of onset of symptoms was 58.17 (SD = 13.52), with the youngest age of symptom onset 23 and the oldest 79. Duration of symptoms, on average, was approximately 28.3 months (SD = 29.8), with the most recent onset of symptoms 5 months prior to data collection and the longest duration of symptoms recorded at 170 months. Only one patient was considered a hospice, terminal patient. Specific patient demographic information beyond what is presented was not collected.

Design and Procedures

ALS patients-caregiver dyads attending a multidisciplinary clinic were solicited for voluntary involvement in the larger study. Information regarding the nature of this study was presented to patients and caregivers upon admission to a several-hour clinic visit in which they met with a physician, a nurse, occupational therapist, physical therapist, nurse counselor, nutritionist and speech pathologist, and other members of the multidisciplinary team. Because patient data was taken from a larger study, information on the total number of patients approached for participation is not available. However, of 87 caregivers invited to participate in the original study, 75 (86.2 percent) chose to do so. Of these, 22 (29.3 percent) were not spousal caregivers and so not included in this study, leaving a total of 53 caregivers (70.7 percent) represented in this investigation. Patients and caregivers were approached to participate once deemed cognitively competent by the physician and/or nurse. Any potential participant assessed as cognitively compromised was not included in this study.

The physician and/or nurse communicated patient willingness and appropriateness to participate to data collectors, who then (whether for patient or caregiver) met in the patient's examination room with both the patient and caregiver to describe their aspect of the study (reiterating what was mailed ahead of time) and answer any questions. Not all caregiver participants were joined in their involvement by their patient spouses, and vice versa. For the purposes of this investigation, however, only dyads in which both the patient and spousal caregiver participated were included (a total of 53). At this point, informed consent was obtained separately for the caregivers and for the patients before any measures were administered (see Appendix A). The caregiver demographic questionnaire and all other measures were individually completed by caregivers and patients, with the assistance of separate data collectors. Most caregivers did not require data collector assistance; however patients were automatically assisted regardless of disability or level of communication difficulty to ensure standardized administration of protocols.

Measures were shown to patients while being read aloud. Caregivers were not permitted to assist patients in completing their protocols, nor were patients allowed to corroborate on information provided by the caregiver. Some caregivers were unable to complete their protocols while in clinic and instead chose to return them to the investigator of that component of the larger study via an investigator-addressed, stamped envelope provided. Only data collected for both spouses will be included. As this may result in temporal inconsistencies between spousal dyads data collection, this is a limitation of this investigation and will be discussed further later.

Instruments

In addition to demographic information (see Appendix B), as part of the larger study caregivers completed numerous and various measures, as did patients with the exception of a formal demographics questionnaire. Specific to this investigation are the measures outlined next. All questionnaires, for both patients and caregivers, were administered in the same order.

Predictive Measures

Relationship Satisfaction. Relationship satisfaction in this study was defined as the score on the Dyadic Satisfaction subscale of the Dyadic Adjustment Scale (DAS;

Spanier, 1976; See Appendix C). The DAS is a frequently used, 32-item inventory for married or unmarried, cohabitating couples, and comprised of four subscales: Dyadic Satisfaction (the degree to which the couple is satisfied with the present state of the relationship and is committed to its continuance), Dyadic Consensus (the degree to which the couple agrees on matters of importance), Affectional Expression (the degree to which the couple is satisfied with the expression of affection and sex in the relationship), and Dyadic Cohesion (the degree to which the couple engages in activities together) (Manne et al., 1999; Spanier, 1976). Each item is rated on a 0-5 scale, with the exception of one item regarding degree of "happiness" with relationship that is rated 0-6. The DAS was designed to be used either as an overall measurement of dyadic adjustment or as separate measures based on the scores of only one subscale "without losing confidence in the reliability and validity of the measures" (Spanier, 1976, p. 22).

Initial validation yielded criterion related validity (t-test assessing the difference between the mean scores of the married versus divorced groups was significant at the .001 level), construct validity (0.86 for married respondents and 0.88 among divorced participants, $p < 0.001$; factor analysis), and content validity (as assessed by three judging experts) (Spanier, 1976). The DAS and each of the four subscales were determined to be reliable, as assessed using Cronbach's Coefficient alpha (DAS =.96, four subscales ranged between .73 to .94) (Spanier, 1976). A confirmatory analysis was conducted 6 years after the original, and internal consistency for the total scale was indicated ($\alpha = 0.91$) (Spanier & Thompson, 1982). Since its development, the DAS has been used extensively as a global measure of marital satisfaction, and has been shown to have high internal consistency, convergent validity, predictive validity, and stability (Vaughn &

Baier, 1999). It has also correlated highly with other measures of relationship satisfaction.

With regard to the Dyadic Satisfaction subscale alone (to be utilized in this investigation), initial factor analysis loaded 10-items on the dyadic satisfaction factor (minimum loading of .32) (Spanier, 1976). Reliability of the satisfaction subscale was .94 (Spanier, 1976). The satisfaction subscale has been found to be psychometrically sound as a stand-alone measure of marital satisfaction, and when examining the variance accounted for by the DAS as a whole, this subscale contributed a large amount of it (Vaughn & Baier, 1999). A higher score on the satisfaction subscale of the DAS indicated a higher level of relationship satisfaction, and a lower score indicated a lower level. Internal reliability and validity are satisfactory. A minor adjustment was made to each question of the original subscale, in an effort to assess the caregiver's response related to status on that item at the time of completion as well as prior to ALS diagnosis (see Appendix C). It is unlikely that these changes will alter the validity of this scale, as the original scale is completely intact and only additions were made in order to gather potentially useful information.

Competence. Caregiver competence was measured by the Perceived Caregiving Competence questionnaire, comprised of 4 Thurstone-type questions (rated 1-4) regarding thoughts and beliefs about how competent participants perceived themselves to be (see Appendix D). This questionnaire was developed by Pearlin and his colleagues (1990) as part of a larger conceptual framework to assess numerous variables related to, or perhaps moderators of, the amount of distress experienced by caregivers. The method developed to assess this construct seems to be an acceptable one, as it appeared to be independent of other related constructs [the highest it correlated with other constructs was with "role gain" ($r = 0.32$), an idea that caregivers may find some inner growth or personal benefit from the role of caregiving] (Pearlin et al., 1990). Competence is defined as the composite score on this instrument, from 4 to 16. Although it may seem ideal to assess caregiver competency objectively, as was summarized in Stebbins and Pakenham (2001), caregivers' perception of their situation has been shown to be a more reliable predictor of adjustment than more objective measures. In addition, in the data set considered here, as examined in the larger study, caregiver perception of level of care, for example, correlated positively and significantly with an objective measure of patient functioning, indicating that these caregivers are accurate reporters. Finally, in this study using a subjective measure may be more reliable in that it assesses the cognitive appraisal of these spousal caregivers, as do the other measures incorporated in this investigation (relationship satisfaction and level of care). Maintaining consistent means for measurement of caregiver variables (subjectively assessed as opposed to a combination of objective and subjective measures) is more appropriate in an investigation of emotionally related variables (patient QOL as potentially influenced by caregiver emotions).

Level of Care. The amount and type of care provided to the patient by the caregiver was assessed by the Level of Care Index (see Appendix E). This instrument is a three-item, subjective questionnaire completed by the caregiver that yields the total number of hours per week care is provided, as well as a summary of both direct (i.e., bathing or showering, assistance with feeding, getting in and out of bed and chairs) and indirect (i.e., housework, grocery shopping, giving medication, preparing meals) tasks of daily living. The caregiver's objective demands are then categorized, based on the combined score, into one of 13 levels, with Level 13 indicating the highest amount of care provided. Level of care was considered statistically first, as it is potentially a source of error variance.

Important to discuss at this point is why patient physical functioning is not included as a potential predictive variable affecting patient QOL in this investigation. Patient physical functioning was assessed by the clinic neurologist using the ALS Functional Rating Scale (ALSFRS; ACTS Phase I –II Study Group, 1996). The ALSFRS is a 40-point scale consisting of 10 items that assess bulbar, limb, and respiratory functioning of ALS patients, and scores range from 0 to 40 and indicate overall functioning capabilities of patients, with lower scores indicating poor functioning. As previously discussed, physical functioning was not found to be a significant predictor of patient QOL (Bromberg & Forshew, 2002; Robbins et al., 2001; Simmons et al., 2000), and, therefore, will not be included as a potential mediating factor here. In addition, the variables under investigation were represented by data collected from caregivers, and the caregiver-completed LOC measure provided an indication of physical needs of the patient while maintaining consistency by incorporating caregiver perception.

The ALSFRS and the LOC rating for this data set have already been examined for relationship in the original investigation from which this sample of caregivers were obtained (Murphy, 2002). Murphy's analysis indicated that there was a moderately strong relationship between caregivers' perception of level of care required by patients (as measured by the LOC index) and the actual physical functioning of patients (as measured by the ALSFRS)($r = -.690$, $p < .001$, two-tailed), suggesting the caregivers in this study accurately perceived the extent of care they provided to the ALS patients.

Criterion Measure

Quality of life. Patient QOL was measured using the MQOL questionnaire, a self-report questionnaire consisting of 16 questions with responses ranging from 0 to 10 and the single-item subjectively rated overall QOL measure (the MSIS) (see Appendix F). This measure was found to be reliable and valid for use with the chronically ill population, including cancer, HIV, and ALS patients (Cohen, et al., 1995; Cohen, Hassan, et al., 1996; Cohen, Mount, et al., 1996; Pratheepawanit et al., 1999; Robbins et al., 2001; Simmons et al., 2000). Specifically relevant to ALS, the MQOL questionnaire is considered a better measure than many others because it is less heavily weighted toward physical functioning (Robbins et al., 2001; Simmons et al., 2000). This measure may permit a better representation of QOL in the ALS population than even some ALS-specific questionnaires (i.e., the SIP/ALS-19 or ALSAQ-40), because its focus is not entirely on physical experiences and instead seeks to also assess psychological, support, and existential factors via distinct subscales (Cohen et al., 1997).

The MQOL has been revised since its original development (Cohen et al., 1995), and currently includes, in addition to the MSIS, five sub-measures assessing five domains of functioning, and the total QOL score (the average of the five sub-measure scores) (Cohen, Hassan, et al., 1996; Cohen, Mount, et al., 1996; Cohen et al., 1997). The five sub-measures consist of: physical symptoms, physical well-being (a single item factor), psychological symptoms, existential well-being, and support. Cohen and colleagues have established the internal consistency of the MQOL total score and subscales scores with 109 HIV/AIDS patients (MQOL total, 0.83; physical symptoms, 0.84; psychological symptoms, 0.77; existential well-being, 0.86; support, 0.83; Cohen, Hassan, et al., 1996), 247 cancer patients (MQOL total, 0.89; physical symptoms, 0.85; psychological symptoms, 0.84; existential well-being, 0.87; support, 0.84; Cohen, Mount, et al., 1996), and 143 palliative care patients (1 ALS patient and 142 cancer patients) across eight centers (MQOL total, 0.83; physical symptoms, 0.62; psychological symptoms, 0.81; existential well-being, 0.79; support, 0.74; Cohen et al., 1997). In addition, Pratheepawanit and colleagues (1999) compared the MQOL to the Patient Evaluated Problem Scores (PEPS) with 52 advanced cancer palliative care patients and found that the MQOL showed excellent internal consistency ($\alpha = 0.90$) (physical symptoms, $\alpha = 0.88$; psychological symptoms, $\alpha = 0.89$; existential subscale, $\alpha = 0.86$; and support subscale, $\alpha = 0.73$) (Pratheepawanit et al., 1999).

For this investigation, both the MQOL total score and the MSIS for each patient were used to represent patient rating of QOL. Both measures were included to allow for representation of QOL that is direct and subjective, but that also reflects specific aspects relevant to QOL (from five domains of functioning). The MSIS was considered the single criterion variable in the regression equation, with the MQOL total score being statistically considered as a predictive variable. The MQOL total score was included in the regression equation as a means to account for factors of QOL, as rated by the patients, that may be measured by the 16-item MQOL *before* assessing the influence of caregiver variables under investigation.

Chapter 3: Results

The purpose of this investigation was to examine the relationship between caregivers' relationship satisfaction and caregivers' self-perceived competency. Also, this study evaluated how much, if any, of the variability in patient QOL is explained by these caregiver variables after the patients' level of care and other patient-rated QOL factors are considered. Analyses of this present investigation utilized the SPSS 11.0.

Descriptive Statistics

A summary of caregiver and patient performances on measures of interest in this investigation is presented (in Table 2).

Caregivers scored a mean of 5.72 (SD = 4.09) on the Level of Care Index, with a lowest reported score of 1 and highest of 13 (with the possible range a minimum of 1 and maximum of 13). The score is the level assigned to the total number of direct and indirect daily living tasks and total number of hours of care provided per week combined. A level 13 indicates the most intensive amount of care provided. A score of 5.72 indicates that, on average, patients were not severely debilitated and did not require the most intensive amount of care.

Caregivers scored a mean of 41.27 (SD = 6.09; N = 49) on the Dyadic Satisfaction Subscale on the Dyadic Adjustment Scale. The lowest recorded score was 21 and the highest was 49. The Dyadic Satisfaction Subscale is comprised of 10 questions, assessing several characteristics of the marital relationship (i.e., how often is separation considered, frequency of quarrels, general assessment of how well "things

Table 2

Descriptive Information

ALS Caregivers' Scores

Instrument	Mean	SD	Range	Minimum	Maximum
Level of Care	5.72	4.09	12	1	13
Relationship Satisfaction	41.27	6.09	28	21	49
Caregiver Competency	14.00	1.79	16	10	16

ALS Patients' Scores

Instrument	Mean	SD	Range	Minimum	Maximum
QOL Total	7.63	1.18	5.32	4.53	9.85
QOL –Single-item	7.57	1.62	7	3.00	10.00

between you and your mate are going," etc.). A higher score on the satisfaction subscale of the DAS indicates a higher level of relationship satisfaction, and a lower score indicates a lower level.

Caregivers scored an average of 14 (SD = 1.79) on the self-rating of caregiver competency. The lowest reported score was 10 and the highest reported score was 16. The Perceived Caregiving Competence questionnaire is a subjective, four-item scale that is scored by adding the total of the four items, with a minimum of 4 and maximum of 16. A score of 10 indicates that caregivers in this sample believed they are at least "a little" or "somewhat" (for example) competent as caregivers, confident within the role of caregiver, or feel that they are good caregivers.

The McGill Quality of Life (MQOL) questionnaire provided a total score for patients, which indicates overall QOL and is the average of scores on 16 items related to physical, psychological, social, and existential experiences of the patient. The average patients' total score on the MQOL was 7.63 (SD = 1.18), with a lowest recorded patient score of 4.53 and a highest recorded patient score of 9.85. Patients scored an average of 7.57 (SD = 1.62) on the McGill Single Item Scale (MSIS), the single-item self-reported overall QOL measure that is part of the MQOL. The lowest reported score on this item was 3 and the highest reported score was 10. Higher scores on these measures indicate better quality of life, and scores on both of these measures range from a possible minimum of 0 to a maximum of 10. Average scores of 7.63 and 7.57 indicate that, on average, patients in this sample have relatively high QOL, both when considering the average of scores on a multidimensional measure and when self-reported (respectively).

Inferential Statistics

Statistical analyses of the inferential data collected from the Level of Care Index (LOC), Dyadic Satisfaction Subscale of the Dyadic Adjustment Scale (DAS), the Perceived Caregiver Competence questionnaire, the total score on the McGill Quality of Life questionnaire (MQOL), the Single-Item Scale of the MQOL (MSIS), and the Support Subscale of the MQOL were completed using correlational methods and regression analyses to determine the relationship among, and predictive value of, the variables. Regression uses the correlations between variables to create an equation that allows for the prediction of one variable of interest based on known scores on the other variables. What is measured is the amount of change (variability) in one variable (criterion variable) that can be determined by the relationship of that variable with other variables (predictors). The goal of regression is to find the equation that produces a "best fit line" that allows for this prediction and minimizes the distance (error) between known scores and what is expected (predicted) given that relationship (as defined by an equation) (Gravetter & Wallnau, 2000, p. 559). Multiple regression analysis, used here, identifies the linear relationships between a set of predictors and a single criterion and determines the ideal combination of the set of predictors to produce the most accurate predicted scores on the criterion (Licht, 2001). Each predictor variable is weighted based on their relationship to the criterion variable.

Hierarchical multiple regression is a series of multiple regression analyses in which a new predictor is added, one at a time, into the equation to predict the given criterion variable. This process identifies the degree of variance unique to each predictor as it is entered into the equation. If the variance is not statistically significant for an entered predictor, then that predictor does not contribute uniquely to the variance above what the previously entered predictor has contributed. In this investigation, hierarchical multiple regression was used to assess prediction of patient quality of life and explain relationships that exist among the overall quality of life on a multiple-subscale measure, level of care rating, relationship satisfaction score, and caregiver competence rating. The strength of the correlations between the predictors (the total score on the MQOL, level of care, relationship satisfaction, and caregiver competence), and the criterion variable (patient quality of life) determines the accuracy of the predictions among variables.

Correlation Analyses

Correlational analyses between the variables assessed in this study are summarized in Table 3.

Table 3

Bivariate Pearson Product-Moment Correlations among Variables

Variable	Relationship Satisfaction	Caregiver Competency	MQOLT	MSIS	LOC
Level of Care	-.082	.213	-.306*	-.222	---
Relationship Satisfaction	---	.073	.084	.061	-.082
Caregiver Competency	.073	---	-.176	.033	.213
MQOLT	.084	-.176	---	.565**	-.306*
MSIS	.061	.033	.565**	---	-.222

* $p < .05$ (two-tailed)
** $p < .01$ (two-tailed)

Level of Care. Level of care provided by caregivers to patients, as assessed by the Level of Care Index, was negatively correlated with total QOL, as assessed by the total score on the MQOL ($r = -.306$, $p < .05$, two-tailed). Although this relationship is significant, it is small, and may be explained by the fact that the MQOL total score includes items related to physical symptoms and well-being. The MSIS score did not correlate with patients' level of care; a finding consistent with the literature (Robbins et al., 2001; Simmons et al., 2000) that asserts that physical functioning and deterioration of that functioning as ALS progresses does not impact patients' self-reported overall QOL.

Quality of Life. Patient QOL as measured by the total score on the MQOL was positively correlated with patient QOL as provided in a single, global, subjective item (MSIS) ($r = .565$, $p < .01$, two-tailed). This finding suggests that patients, when asked to rate their QOL, accurately represent their QOL, as assessed more indirectly by a multidimensional QOL scale. However, this finding does not account for the total variance in patients' global, self-reported QOL, with 69 percent still unexplained by this correlation.

Regression Analysis

Hierarchical multiple regression analysis was conducted to determine if caregivers' relationship satisfaction and caregivers' competency predicted patients' quality of life, independent of level of care required by the patient and after several varied aspects of QOL (from five domains of functioning, as represented by the total score on the MQOL) were considered. The rationale for inclusion of the MQOL total score in the regression equation was that additional factors of QOL, more indirectly rated, would not detract from the subjective experience of QOL (that is more directly assessed using the MSIS). The order of entry of the variables into the regression equation was as follows: MQOL total score, Level of Care, Relationship Satisfaction, and Caregiver Competency.

The results revealed that the total score on the MQOL predicted 32.5 percent of the variance in quality of life, as rated by the MSIS [$F(1, 47) = 24.06$, $p < .05$]. Level of care, caregiver relationship satisfaction, and caregiver degree of perceived competence were not significant predictors of patient QOL. Table 4 presents the results of regression analysis.

Post Hoc Analyses

Level of care and patient physical well-being. The caregivers' perceptions of the amount of care they provide to the ALS patients, as measured by the Level of Care Index, was significantly and negatively correlated with the patients' rating of physical well-being, as measured by the physical well-being subscale of the MQOL ($r = -.410$, $p < .01$, two-tailed). This post-hoc analysis was conducted to identify the relationship, if any, between level of care required by the patients (as assessed by the caregivers) and their subjective experience related to physical functioning and status. It was thought that perhaps level of care did not predict patient QOL because its influence was already accounted for within the overall QOL score on the MQOL within the physical symptoms or physical well-being subscale. There was no correlation between level of care and physical symptoms subscale.

Table 4

Summary of Hierarchical Regression Analysis for Variables Predicting Patient Quality of Life

Model	R	R^2	Adjusted R^2	Std. Error of the Estimate
MQOL total	.582	.339	.325	1.30940

Analysis of Variance

MQOL total	df	Sum of Squares	Mean Sq.	F	Sig.
Regression	1	41.254	41.254	24.062	.000
Residual	47	80.582	1.715		
Total	48	121.837			

Beta Coefficient

Variable	Coefficient	Std. Error	Std. Coefficient	t	Sig.
MQOL total	.763	.156	.582	4.905	.000

Excluded Variables

	Beta In	t	Sig.	Partial Correlation	Collinearity Stats.
Level of Care	-.110	-.877	.385	-.128	.896
Relationship Satisfaction	.012	.098	.922	.015	.993
Caregiver Competence	.093	.765	.448	.112	.964

Physical functioning and QOL. As level of care did not correlate with patient self-rated QOL but a negative relationship was identified between level of care and overall patient QOL (as assessed by the total score on the MQOL), an additional analysis was conducted to identify whether or not patient physical functioning (as assessed by the ALSFRS) correlated with patient QOL — whether self-reported or multidimensional. Patient physical functioning did not correlate with patient self-rated QOL nor with patient QOL as assessed by the total score on the MQOL that includes physical symptoms and physical well-being ratings. However, patients' physical well-being (as assessed by the MQOL subscale) was positively correlated with patient physical functioning, as assessed by the ALSFRS ($r = .293$, $p < .05$, two-tailed). This finding is consistent with the finding presented above identifying a relationship between patient physical well-being and his or her degree of physical functioning (as assessed by the level of care index).

Patient and caregiver QOL. Due to the absence of a predictive relationship between the caregiver variables of relationship satisfaction and competence and the patient variable of self-rated QOL, an analysis was conducted to investigate if caregivers and patients were similar in their self-rated QOL, overall QOL, or factors of QOL assessed by the MQOL submeasures (see Table 5). Caregiver self-rated QOL (as assessed by the MSIS) was positively and significantly correlated with: patient overall QOL as assessed by the MQOL ($r = .280$, $p < .05$, two-tailed), patient psychological symptoms ($r = .313$, $p < .05$, two-tailed), patient existential well-being ($r = .436$, $p < .01$, two-tailed), and patient-rated support ($r = .354$, $p < .05$, two-tailed). In addition, positive relationships were identified between caregiver and patient existential well-being ($r = .465$, $p < .01$, two-tailed) and caregiver support and patient existential well-being ($r = .319$, $p < .05$, two-tailed). Of note, caregiver overall QOL, that includes several domains of functioning, was not significantly correlated with any patient QOL scores or subscores.

Table 5

Bivariate Pearson Product-Moment Correlations Among Caregiver and Patient QOL Variables

Variable	CG MSIS	CG MQOLT	CG Phys Sxs.	CG Phys Well-Being	CG Psych	CG Exist	CG Support
Pt. MSIS	.165	-.025	-.135*	-.111	.086	.215	.041
Pt. MQOLT	.280*	.092	.064	-.009	.001	.217	.196
Pt. Phys Sxs	-.023	.010	.048	-.031	-.016	-.034	.086
Pt. Phys Well-being	-.005	.044	.061	-.052	-.049	.138	.121
Pt. Psych	.313*	-.055	.008	-.083	-.008	.025	-.046
Pt. Existential	.436**	.205	-.004	.102	.051	.465**	.319*
Pt. Support	.354*	.184	.074	.138	.083	.246	.219

* $p < .05$ (two-tailed)
** $p < .01$ (two-tailed)

Findings Relevant to Research Hypotheses

Obtained data was reviewed for support of the hypotheses under investigation.

(1) Relationship satisfaction, as rated by the spousal caregivers, and how competent caregivers perceive themselves to be would predict patients' QOL independent of level of care required by patients and after several varied aspects of QOL (from five domains of functioning, as represented by the total score on the MQOL) are considered.

(2) Relationship satisfaction, as rated by the spousal caregivers, does not relate significantly to how competent caregivers perceive themselves to be.

Hypothesis 1. Hypothesis 1 was analyzed by hierarchical regression analysis. The results indicated that relationship satisfaction and caregiver competency were not significant predictors of subjectively rated patient QOL. A composite score that includes a variety of indirectly measured factors of QOL was the best predictor of patient-rated quality of life. Thus, hypothesis 1 was not supported.

Hypothesis 2. Hypothesis 2 was assessed through correlational methods. The results indicated that relationship satisfaction and caregiver competency were not significantly correlated (r = .073, p < .01, two-tailed). Therefore, hypothesis 2 was supported.

Summary of Findings

A patient's total QOL score predicted a significant amount of variance in subjectively, self-reported patient QOL. In addition to separate demographics questionnaires (Appendix B), a sample of 53 ALS patients and their 53 spousal caregivers completed the following measures: the McGill Single Item Scale and the McGill Quality of Life questionnaire; the Level of Care Index, the Dyadic Satisfaction subscale of the Dyadic Adjustment Scale, and Perceived Caregiver Competence. The findings included:

1. The mean age of the caregivers was 59.43 (SD = 13.6); the mean age of patients was 60.48 (SD = 13.32).
2. The majority of spousal caregivers were female (N = 37, 69.8 percent).
3. The majority of the caregivers were Caucasian (N = 51, 96.2 percent).
4. The mean patient age of onset of ALS symptoms was 58.17 (SD = 13.52), with the youngest patient 23 years old and the oldest 79.
5. Caregivers reported a mean Level of Care of 5.72 (SD = 4.09), suggesting patients' required a low to moderate amount of care.

6. Caregivers reported a mean relationship satisfaction score of 41.27 (SD = 6.09, N = 49), and a mean perceived competency score of 14 (SD = 1.79), suggesting caregivers were relatively satisfied in their marital relationships and perceived themselves to be competent in the role of caregiver.
7. Patients reported a mean quality of life score on the subjectively rated, single-item scale of 7.56 (SD = 1.62), and a mean total quality of life score on the comprehensive quality of life measure of 7.63 (SD = 1.17). These scores suggest that patients have a relatively high degree of QOL.
8. When caregivers' relationship satisfaction and caregivers' competency were entered into a regression equation, neither variable significantly predicted patients' QOL.
9. Patients' scores on two separate measures of quality life were associated, with patients' total quality of life score significantly predicting the score on their subjectively-rated, single-item score in a regression equation.
10. Level of care was not a significant predictor of patients' self-rated quality of life, and was negatively associated with patients' total quality of life score.
11. Level of care was negatively correlated with patients' rating of physical well- being, and patients' physical function (ALSFRS scores) was positively correlated with physical well-being.
12. Level of care did not significantly correlate with caregivers' ratings of competency or relationship satisfaction.
13. Patients' physical functioning did not correlate with patient QOL, whether self-rated or indirectly rated.
14. Caregivers' self-rated QOL positively correlated with patients' ratings of overall QOL, psychological well-being, existential well-being, and support.
15. Caregivers' and patients' scores of existential well-being were positively related.

16. Caregivers' ratings of support were positively correlated with patients' existential well-being.

Chapter 4: Discussion

The present investigation examined the relationship between caregiver-rated relationship satisfaction and caregiver perceived competency, and their ability to predict patient quality of life in a sample of ALS spousal patient-caregiver dyads. Overall, the findings do not suggest that either caregiver variable is responsible for observed variance in QOL of their spousal patients. The only significant predictive relationship was between patients' total QOL score (that reflects status on a variety of factors from several domains of functioning) and their subjectively rated, self-reported QOL.

Regression results. It was hypothesized that relationship satisfaction of caregivers and how competent they perceive themselves to be as caregivers would both significantly impact the QOL experience of their spousal patients. However, the best predictor of this single criterion variable was the patients' own factors, as they were combined in an overall QOL rating. This finding did not support the reviewed literature that identified predictive relationships between caregiver and patient variables (namely, depressive symptoms, anxiety, subjective well-being or QOL, and relationship satisfaction) (Bookwala & Schulz, 1996; Dennis et al., 1998; Dorfman et al., 1996; Gaelick et al., 1985; Goodman & Shippy, 2002; Manne et al., 1997; Rabkin et al., 2000; Tesser & Beach, 1998; Tower & Kasl, 1995; and Williamson & Schulz, 1990). Perhaps this lack of association relates to the fact that relationship satisfaction and caregiver competence, in this investigation, are caregiver variables and a patient variable was the criterion. In addition, the sample size was small and measurements used had not necessarily been previously validated with this population. These and other limitations related to sample bias and measurement are discussed in more detail later.

Level of care and physical functioning. The level of care required by patients (as rated by care provided by caregivers) was not a significant predictor of patient QOL, as assessed by patients' self-rated QOL. Murphy's (2002) findings in the larger study of this ALS caregiver population indicated that a high level of care was associated with reduced functional abilities in patients, as level of care was significantly and positively correlated with an objectively measured level of patient physical functioning (the ALSFRS). Her finding suggests that caregivers accurately perceived the extent of care provided to ALS patients. The lack of association between level of care and patient QOL, along with Murphy's finding, suggests that ALS patient physical functioning does not predict their self-rated QOL. Further, patient physical functioning, as assessed by the ALSFRS, did not correlate with either self-rated QOL or with overall, objectively rated QOL. These findings are consistent with previous study results that assert patient QOL is not dependent on disease severity (as assessed by physical functioning) (Bromberg & Forshew, 2002; Robbins et al., 2001; Simmons et al., 2000). In addition, post hoc analysis indicated that level of care was significantly and negatively correlated with patients' physical well-being, while patients' physical functioning (as assessed by the ALSFRS) was significantly and positively correlated with patients' physical well-being. These findings are consistent, and suggest that ALS patients do not experience declines in physical functioning as impacting their physical status, as it relates to overall QOL.

Relationship satisfaction. Caregivers' self-reported relationship satisfaction was not a significant predictor of patient quality of life. According to the literature, high relationship satisfaction has been associated with lower levels of strain and higher levels of caregiver satisfaction (Dorfman et al., 1996), lower levels of depression (Kramer, 1993; Morris et al., 1988), and lower caregiver perceived burden (Dorfman et al., 1996; Manne et al., 1997). Collectively these factors contribute to QOL. However, in these studies all of the variables under investigation were caregiver variables and in this study caregiver variables were considered within a predictive relationship with a patient variable.

Of interest with regard to relationship satisfaction, despite the absence of the hypothesized association between relationship satisfaction and patient QOL, is the degree to which this sample of caregivers was satisfied in their spousal relationships with the patients. Overall, caregivers indicated a mean rating of 41.27 (SD = 6.09, N = 49) for relationship satisfaction, which is comparable to Spanier's original standardization sample of married participants (M = 40.5, SD = 7.2; Spanier, 1976), indicating an average degree of relationship satisfaction as compared to the general population of non-caregivers. This finding is significant, in that it may contradict what may be (erroneously) assumed about the impact of chronic illness and the accompanying shifts in equality that are inevitable within the patient-caregiver spousal relationship: that the quality of the spousal relationship cannot be maintained. These present results are consistent with Cutrona's (1996) claim that, despite facing the strains and adjustments of chronic illness, marital quality can remain strong.

Caregiver competence. Caregiver competence also did not predict patient QOL as was hypothesized. Like relationship satisfaction, the literature has indicated that caregivers' degree of competency and self-efficacy is a buffer in protecting their overall psychological and emotional experience, as higher self efficacy has been associated with lower levels of distress (Bandura, 1982; McClenahan & Weinman, 1998); lower perceived competence has been associated with higher ratings of caregiver strain and depression (Dorfman et al., 1996; Haley et al., 1987; McClenahan & Weinman, 1998; Pearlin et al., 1990; Stebbins & Pakenham, 2001). The beneficial impact of caregiver competence (or self-efficacy) on emotionally related variables support the construct of caregiver competence as a predictive variable when considering QOL. However, support for this suggestion may be more reliably found if predictive and criterion variables are collected from either caregivers or patients but not in regard to a relationship between both.

Of note with regard to competency ratings, caregivers in this study, on average, perceived themselves to be competent in their duties as caregivers (M = 14, SD = 1.79). Given that they reported an average level of care of 5.72, this suggests that caregivers perceived themselves to be competent even when performing such duties as assistance with feeding, bathing, toileting, and mobility, and providing medical care, physical assistance, and managing household affairs. In addition, when considered together with relationship satisfaction findings, these results suggest that caregivers in this sample adjusted well to the demands of their new role as caregivers and that this adjustment did not negatively impact their spousal relationship. This is an especially beneficial finding for the ALS community, given that 78 percent of primary caregivers of these patients are spouses untrained in providing care.

Summary of Hypothesis 1. The two caregiver measures examined here — relationship satisfaction and caregiver competency — were included as possible predictors of patient QOL based on the literature supporting the phenomenon of emotional convergence. Because of the relevant literature (as reviewed above), it was thought that the ability of one person's emotional status to influence the emotional experience of another would be evident here in terms of a predictive relationship between two variables that relate to emotional experience (satisfaction within a spousal relationship and one's own perceived self-efficacy as a caregiver) and a measure of QOL. Although the construct of emotional convergence has not been examined sufficiently within the context of a spousal patient-caregiver relationship, it has been demonstrated within intimate and spousal relationships of a nonmedical population (Anderson, 2001; Hatfield et al, 1992, 1994; Wild et al., 2001). The emotional convergence model emphasizes the importance of similarity between people for convergence to occur (Festinger, 1954; Sullins, 1991), and that the reciprocal, interdependent nature of marital relationships make convergence inevitable (Cutrona, 1996; Goodman & Shippy, 2002; Hatfield et al., 1994). Given the unique and certain interdependent nature of the patient-caregiver relationship, it was thought that partners would assuredly influence one another's emotional or psychological status. However, a limitation, again, relates to using predictive variables of one spouse and the criterion of the other spouse. This may be beneficial in measuring the same variables across people, but was not, in this case, as the variables were so different in nature and only loosely related to emotional status. This is an additional limitation — that the constructs being measured were not consistent across subjects. Future studies attempting to support the occurrence of emotional convergence within spousal patient-caregiver dyads should use the same measures to assess the same variables (i.e., depressive symptoms in both spouses, each spouse's QOL, etc.) across subjects.

Summary of Hypothesis 2. The second hypothesis, that relationship satisfaction would not be associated with how competent caregivers perceive themselves to be, was supported, as no significant relationship was found. The implication of this finding is that spouses assuming the caregiver role out of necessity do not necessarily suffer a reduction in their marital satisfaction because of how well or how poorly they are able to manage the demands of the caregiving experience and may maintain a high degree of relationship satisfaction with their spousal patient regardless of disease progression. No relationship between these variables is a more positive finding than a negative correlation, because it would not be beneficial for spousal caregivers' satisfaction to be influenced by their competency, given that demands may increase as the ALS patient deteriorates physically. This would unfairly punish caregivers who would become less satisfied in their marital relationships as more advanced or difficult caregiving tasks arise.

Patient quality of life. Perhaps the most significant finding of this investigation is that none of the variables hypothesized to account for the variance in QOL of patients did so. None of the variables predicted individual QOL above and beyond a detailed account of QOL, as defined by the total score on the MQOL questionnaire. What was identified was a relationship between patient variables. This finding, although not as expected, is a finding for just that reason: it suggests that QOL is more broadly defined for patients and not largely dependent on caregivers, as one might think (and as was thought here). Patient QOL appears to be more independently determined, at least with regard to the variables considered here. This is not to say that specific patient emotional experiences that contribute to QOL would not be influenced by the emotional experiences of caregivers, as is suggested by the detailed review of emotional convergence; but, that QOL as a construct contains far more than simply emotional well-being. Additional research to more accurately understand the factors that contribute to ALS patient QOL, and identify means to more precisely measure this construct, must be conducted.

Of note, patients in this study on average rated their QOL as high both when subjectively rated on the MSIS (M = 7.56, SD = 1.62), and when assessed more indirectly via the total score on the MQOL, that includes patients' status on a variety of items within several domains of functioning (M = 7.63, SD = 1.17). These findings are in comparison to the MQOL authors' study involving 109 HIV/AIDS patients (MSIS: M = 6.9, SD = 2.3; MQOL total: M = 6.7, SD = 1.4; Cohen, Hassan, et al., 1996) and 247 cancer patients (MSIS: M = 7.2, SD = 2.3; MQOL total: M = 7.6, SD = 1.5; Cohen, Mount, et al., 1996). This finding is particularly interesting in that, as compared to other medically ill populations who have the availability of effective treatment options and a longer life expectancy than is typical of ALS, these patients experience similar or better quality of life.

Caregiver and patient QOL. In an effort to demonstrate the possible occurrence of emotional convergence within this sample, a post-hoc analysis was conducted to investigate the relationship between emotionally laden caregiver and patient variables, namely: self-rated QOL, total QOL, and subscales of the MQOL. A positive, significant relationship was identified between caregiver self-rated QOL and patient scores of psychological, existential, and support functioning. In addition, patient existential well-being was positively related to caregiver existential well-being and caregiver support. The relationships identified between caregiver and patient emotional variables suggest that it is possible for emotional convergence to be taking place within this sample of ALS spousal caregiver-patient dyads. Of note, however, is that more patient ratings were related to caregiver QOL than vice-versa. In fact, no caregiver subscales correlated with patient QOL, only self-rated caregiver QOL. In following Anderson's (2001) research on the influence of power on emotional convergence, it may be possible that the patients in these dyads have more power in the relationship than caregivers — the opposite of what was considered in hypothesizing this investigation. It may be possible that patients actually exert more power within the dyadic relationship because they, and their illness, determine and even dictate the activities of the dyad.

Of note, caregiver QOL, either self-rated or overall QOL, was not significantly related to patient physical symptoms or well-being, suggesting that the severity of patient functioning does not negatively impact caregiver experience. This is consistent with Murphy's (2002) findings, that patient physical functioning (as assessed by the ALSFRS) does not relate to caregiver psychological morbidity or QOL (as assessed by a different QOL measure).

Emotional convergence. An issue of discussion at this point relates to the influence of patient communication on the occurrence of emotional convergence. Although patient physical functioning did not relate to caregiver experience, perhaps the nature of patient physical limitations may play a role in the presence of emotional convergence and the ability to identify its influence. Specifically, perhaps the ability of patients to communicate verbally influences whether or not patients and caregivers are more likely to converge emotionally, given that — in the absence of verbal communication of feelings, experience, etc. — caregivers must become more attune to patient states, including emotional. This suggestion is not supported here, as no information on the degree of communication deficits was available and to investigate this hypothesis a longitudinal study with a larger sample would be necessary. But this question warrants consideration in future studies investigating the occurrence of emotional convergence over time between caregivers and patients with ALS, or any chronic illness that includes communication limitations.

In addition, with regard to the recent article by Lomen-Hoerth and colleagues (2003) suggesting the presence of executive functioning deficits in ALS patients (specifically more so in bulbar-onset patients), the issue of the impact of patient emotional functioning on the occurrence of emotional convergence is worthy of further investigation. In other words, perhaps emotional convergence is limited by the extent to which patients are able to self-monitor (as is important with regard to social comparison theory) and/or regulate and communicate their emotions because of the presence of symptoms of dementia, namely executive functioning deficits. If a large proportion of patients in this sample are bulbar-onset patients and the findings of Lomen-Hoerth et al. (2003) that suggest these patients are more prone to frontotemporal lobar dementia are supported, then perhaps emotional convergence was occurring less within this particular sample, or at least less readily accessible to assessment. In addition, if the presence of these executive functioning deficits are more common in ALS patients than has been previously represented in the literature, it is possible that emotional regulation and expression is more atypical in this population than in other chronically ill groups, and, therefore, more difficult to assess and predict in terms of effect on either patients or on caregivers. A limit of the Lomen-Hoerth et al. (2003) study, in addition to potential measurement bias, is that "patients with dementia were more likely to be older, have lower forced vital capacity (FVC), and have a family history of dementia" (p. 1096). This suggests that perhaps the presence of dementia in these patients may be explained by the patients' ages, by the presence of dementia in the family history, or by lower FVC that relates to the amount of oxygen reaching the brain and the potential cause of altered mental state (Lomen-Hoerth, et al., 2003).

Limitations of This Study

There are a number of limitations within the design and measurement of this study that may have minimized or compromised its findings.

One significant limitation of this study relates to internal validity and the degree of confidence with which these results can be interpreted as accurate: specifically, the inattention given to other variables having moderating and mediating effects on QOL.

There are so many potential influencing factors of a subjective, psychosocial experience, such as QOL, that not all could be anticipated or controlled in analysis. Because the goal of this study was not to establish cause(s) of high or low QOL, but to instead strive to better understand the factors that may positively or negatively influence it, only the variables under consideration presently were considered statistically. Unfortunately, due to a small sample size, demographic variables, such as age, education level, and household income that have been found to be important factors in QOL in the literature (Bookwala & Schulz, 1996) were not included in analysis. Sociodemographic variables and other potential confounding variables should be considered in future studies (such as caregiver or patient psychological morbidity, gender, length of time in the relationship, etc.). It is possible that any one of these variables may have interfered with any potential relationship between variables included in this analysis.

Internal validity is further questioned in this investigation because of the lack of documented use of these presently used measures (related to caregiver competency and relationship satisfaction) previously with ALS caregivers. It cannot, therefore, be certain that this study accurately measured how satisfied caregivers are in their spousal relationships with ALS patients, nor how competent they perceived themselves to be in fulfilling the duties inherent in providing care related to the course and progression of ALS. For example, items to assess relationship satisfaction on the DAS (i.e., "How often do you leave the house after a fight?" or "How often do you and your mate quarrel?") may not be applicable to the ALS population due to a caregiver's responsibility to be present for a dependent patient or because a patient may not be able communicate verbally. It was not possible to correct for this limitation in design, as this data was gleaned from a larger study. In addition, limited research exists with ALS patients and caregivers so few measures have been validated for use with this population. Lastly, changes to the DAS, although minimal and only additions not alterations, may compromise the construct validity of that instrument as used in this study. The original caregiver study from which the current data was obtained utilized caregivers other than spouses. Therefore, other, more reliable measures aimed to assess marital relationship satisfaction could not be used.

Another limitation relates to (and threatens) external validity: the unrepresentative sample. Specifically, the sample was almost entirely Caucasian and predominantly from a rural setting. The extent to which these results can be applied to ALS patients of other ethnic and geographical backgrounds is limited. In addition, subjects were voluntary patients and caregivers who chose to attend a multidisciplinary clinic, and may not have included those subjects with higher or lower QOL, poorer or stronger relationship satisfaction, or the extremes of the other variables considered. This inclusion of only patients and caregivers who willingly attend clinic may have inflated the QOL, relationship satisfaction, and competence scores identified in this investigation, in that these subjects may have been more motivated to receive care and/or more positive about their abilities to impact the disease experience than patients and caregivers who chose not to attend clinic. This selection bias may have also skewed the research findings, in that there may have been a restriction in the range of variability of subjects' responses, limiting the strength of relationships during data analysis. This could potentially explain the lack of associations found between relationship satisfaction, caregiver competence, and patient QOL. Repeating this study with a larger, more diverse sample of ALS patients and caregivers from varying geographic locations may produce more significant findings and identify a predictive relationship between the variables investigated here.

With regard to statistical validity, when designing this study the sample was not large enough to maintain power while considering more than two predictive variables. Therefore, only relationship satisfaction and caregiver competence could be considered in this analysis to strive for statistical integrity. However, when the data was analyzed and nonspousal caregiver subjects removed, this sample size was actually smaller than what is recommended for two predictive variables. Cohen (1992) recommends 67 subjects when utilizing a .05 alpha and examining two predictive variables in multiple regression analysis. This present study has only 53, therefore, limiting the degree of power in this analysis and the validity with which these findings can be considered. In fact, with a sample size of 53, an anticipated medium effect size (.50), and alpha set at .05, power in this case is roughly .72 (Kazdin, 1998). As power is the extent to which analyses can detect a statistical difference when it exists, it is possible that the variables hypothesized to predict patient QOL do, to some extent, influence this variable but sample size here limited the ability to identify a relationship. Again, a study to repeat this analysis may be worthwhile, so long as the sample size is at least sufficient.

A threat to construct validity relates to the definition of QOL used in this investigation. This definition is similar, but not the same, as that used in the studies presented that investigated QOL. Therefore, results from those studies may be limited in how much they truly support the premise and rationale (the conceptualization of QOL in this study) for this investigation. In addition, these current findings may not be reliable in addressing QOL via future research or treatment protocols that define QOL differently than is done so here. Defining QOL by one measure, albeit two scales within that one measure, may limit how effectively this construct is captured or represented.

Another threat to construct validity relates to the rationale for investigating these caregiver and patient variables in the first place — the hypothesized mechanism with which caregiver variables were suggested to influence patient QOL; namely, emotional convergence. The literature presented to support the occurrence of emotional convergence (Anderson, 2001; Goodman & Shippy, 2002; Hatfield et al., 1992, 1994; Sullins, 1991; Wild et al., 2001) did so in terms of investigating an emotional state in one person as it influences the emotional state of another. The lack of relationship between caregiver and patient variables in this study may be the result of measuring different constructs across subjects (QOL in one group of subjects and variables other than QOL in another group). The variables assessed presently were not only different in nature but may not have been closely related enough to indicate an effect of emotional convergence, as the caregiver variables were not direct emotional states. This limitation relates more to limits of design when using shelved data — not being able to select appropriate variables and measures to assess those variables when trying to establish validity for the occurrence of a theoretical construct — than to inadequacy of the theoretical construct of emotional convergence. In addition, although emotional convergence was not demonstrated here, it may be more likely to result within patient-caregiver dyads in which patients experience communication limitations and caregiver attunement to patient experience is necessary. This is actually a limitation related to sample bias here, in that patients involved in this study are not necessarily representative of the larger ALS population, in terms of degree and frequency of communication impairment.

An additional limitation relates to temporal inconsistency in measurement. Given that the present data was originally collected as part of two larger studies, and that the patient study was longitudinal in nature, while the caregiver study was not, QOL data may have been collected at a different time than the caregiver variables of relationship satisfaction and caregiver competence. Even though this was a cross-sectional analysis, interpretations of these findings, including the lack of identified predictive relationship, may not be accurate given the dynamic nature of the variables assessed. As all three of these variables relate to the emotional experiences of each spouse, they may vary depending on how each spouse adjusts within the context of ALS, a deteriorating illness. Even if collected at the same time, this data may not reflect the influence of emotional convergence, as "affect similarity is a dynamic process ... (and) there may be a time lag between changes in" the emotional states of spouses (Goodman & Shippy, 2002, p. 273).

A longitudinal investigation in the future should be conducted to follow changes in ALS patient QOL and caregiver variables that may impact that construct as the disease progresses. Findings would likely allow for a better understanding of caregiver and patient responses to the illness, how those responses impact the patients' or caregivers' illness experience, and how best for professionals to provide effective intervention.

Finally, the ability of this investigation to identify a relationship between the hypothesized variables may have been limited in that these variables may not, in reality, be related. It is possible that how satisfied caregivers are in their relationships with their spousal ALS patients, as well as whether or not they feel competent as caregivers, have no influence on patients' QOL.

Conclusion and Future Direction

Based on the potential threats to validity in this study, namely sample limitations, variables measured, and choice of instruments, it is essential that these hypotheses by reinvestigated. The worthiness of this area of research has been outlined and is significant. This study should be replicated in the future with a larger, more representative sample of ALS patients and spousal caregivers, assessing variables related to emotional functioning of both spouses (including QOL) and instruments that accurately measure those variables, to more effectively determine if emotional convergence occurs within this population. Findings would assist professionals working with ALS patients and caregivers in more adequately providing effective intervention that addresses psychological adjustment and emotional coping, by offering additional considerations in assessing patient QOL related to external, caregiver factors. Replicating this study and finding more significant results with a larger and more representative sample of the ALS population is necessary for improving provision of care and guiding effective intervention for both patients and caregivers.

The findings of this study, although not as hoped or hypothesized, are beneficial, in that they direct future research with considerations for more adequately assessing ALS patient QOL and how it is influenced by caregiver variables. Although not found here due to limits related to variables assessed, measures used, and insufficient size and unrepresentative nature of this sample, it is highly likely that emotional convergence as a phenomenon does exist and does occur within the spousal patient-caregiver dyad. This could be assessed longitudinally, including the consideration that patient communication limitations may influence the occurrence of emotional convergence over time.

Psychologists and other professionals should begin addressing the experiences of caregivers of ALS and other chronically ill patients, not only in terms of their own psychosocial needs, but also as they may influence the QOL experience of patients. If future studies can identify more completely the variables — patient or caregiver — that contribute to ALS patient QOL, then treatment alternatives such as couples therapy as another modality for providing intervention could be a supported course of action to improve each members' individual experience with ALS as well as their experience as a united, intimate team facing, fighting, and coping with a debilitating disease. The education that could be offered to ALS caregivers about how they impact their patients' illness experience can provide a source of empowerment — especially when caregivers are often unable to control any other aspect of the disease or their loved ones' struggle — in that they can do more than simply care for the physical and medical needs of their patients.

If these research hypotheses are supported in future investigations, the suggestion may be made for the incorporation of psychological intervention, with caregivers individually or as coupled with patients, into the patients' treatment planning. Further, justification of funding for such psychological interventions as an important part of patient treatment may also be suggested. This will likely be more the case after additional studies are conducted that conclude patients who report a higher rating of QOL utilize fewer medical services and resources.

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Appendix A

PROTOCOL # 97-130EP
DATE: March 4, 1999

CONSENT FOR CLINICAL RESEARCH STUDY

The Pennsylvania State University
College of Medicine
University Hospital • Children's Hospital
The Milton S. Hershey Medical Center

Title of Project: Measuring Quality of Life in Patients with Amyotrophic Lateral Sclerosis: A Pilot Study

Principal Investigator: Zachary Simmons, MD

Other Investigators: Michael Green, MD; Susan Walsh, MSN, RN, Paula Rich, RN

This is to certify that I, ______________________________, have been given the following information with respect to participation as a volunteer in a program of investigation under the supervision of Dr. Zachary Simmons

1. Purpose of the Study: 1) To compare several questionnaires for measuring quality of life in patients with ALS in order to determine which ones provide the best assessments. 2) To attempt to determine the relationship, if any, between physical function and quality of life in patients with ALS.

2. Procedures to be Followed: At each of my ALS clinic appointments (approximately once every 3 months), I will be asked to complete 7 short questionnaires about my physical abilities, my emotions, and the role of religion in my life. This will require approximately 15 minutes. I may decline to participate in this study.

3. Discomforts and Risks: There is no physical discomfort, and there are no physical risks. Some questions may make me feel anxious or cause stress. If I feel uncomfortable, the ALS clinic staff is available to help me. I understand that I may decline to respond to a particular question.

4. a. Benefits to Me: My doctors may develop a better understanding of those factors which affect the quality of my life, and may be able to use this information to improve the quality of my existence.

   b. Potential Benefits to Society: This study may lead to a better understanding of those factors which affect the quality of life in other patients with ALS.

5. Statement of Confidentiality: All records associated with my participation in the study will be subject to the usual confidentiality standard applicable to medical records, and in the event of any publication resulting from the research no personally identifiable information will be disclosed.

6. Right to Ask Questions: I have been given an opportunity to ask any questions I may have and all such questions or inquiries have been answered to my satisfaction. If I have further questions or concerns, or possibly an injury related to this research, I should contact Dr. Zachary Simmons at 717-531-8692 from 8 am to 5 pm Monday through Friday. During other times, I should call 717-531-8521 and ask for the Neurology resident on call.

7. Compensation: I understand that in the event of injury resulting from research neither financial compensation nor free medical treatment is provided for such injury by the University.

8. Voluntary Participation: My participation is voluntary. I further understand that I may withdraw from this study at any time. My withdrawal from this study or my refusal to participate will in no way affect my care or access to medical services.

This is to certify that I consent to and give permission for my participation as a volunteer in this program of investigation. I understand that I will receive a signed copy of this consent form. I have read this form and understand the content of this consent form.

Volunteer's Signature Date

I, the undersigned, have defined and explained the studies involved to the above volunteer.

Investigator's Signature Date

IRB Protocol No. 99-299EP
Date: January 31, 2000

CONSENT FOR CLINICAL RESEARCH STUDY

The Pennsylvania State University College of Medicine
The Milton S. Hershey Medical Center • Penn State Geisinger Clinic

Title of Project: Factors Which Affect the Quality of Life of Caregivers of Patients with ALS

Principal Investigator: Zachary Simmons, MD

Other Investigators: Virginia Murphy-Reiley, MS; Stephanie Friedman, PhD; Barbara Bremer, PhD; Susan Walsh, MSN, RN; Tamara H. Murphy, RNC, BS.

This is to certify that I, _____________, have been given the following information with respect to my participation as a volunteer in a program of investigation under the supervision of Dr. Zachary Simmons.

1. Purpose of the Study: To determine the experience, the quality of life, and the factors that influence quality of life in caregivers of ALS patients. The study involves completing several questionnaires.

2. Procedures to be Followed: At each ALS clinic appointment (approximately once every three months), I will be asked to complete 10 questionnaires about my emotions, the role of religion in my life, my experiences of caregiving, stress, my problem solving methods, my time involvement for giving care, the financial and physical strain of giving care, my social history, the support that I receive from others, and my rating of my current life satisfaction. This will take 30-40 minutes at each appointment.

3. Discomforts and Risks: There is no physical discomfort, and there are no physical risks associated with this protocol. I understand that I may decline to respond to a particular question or questionnaire. I may experience emotional discomfort and become upset due to thinking about my loved ones with ALS and my caregiving experience.

4a. Benefits to Me: I may benefit from the opportunity to speak with an objective person about my thoughts and feelings. I may not benefit from participation in this study. No benefit is guaranteed.

b. Potential Benefits to Society: The information obtained from this study will aid the investigators in understanding the physical, emotional, spiritual, and financial aspects of caregiving to ALS patients.

5. Statement of Confidentiality: All records associated with my participation in the study will be subject to the usual confidentiality standard applicable to medical records, and in the event of any publication resulting from the research no personally identifiable information will be disclosed. Representatives of the HMC Institutional Review Board and Human Subjects Protection Office will have access to my medical records for regulatory review purposes.

6. Right to Ask Questions:. I have been given an opportunity to ask any questions I may have and all such questions or inquiries have been answered to my satisfaction. If I have further questions or concerns related to this study, or if I believe I may have developed an injury that is related to this research, I should contact Dr. Zachary Simmons at 717-531-8692 from 8 am to 5 pm Monday through Friday. During evening hours, weekends and holidays, I should call 717-531-8521 and ask for the Neurology resident on 24-hour call. If I have questions regarding my rights as a research subject, I may contact the Patient Care Advocate in the hospital at 717-531-6311.

7. Compensation: I will receive no monetary compensation for participation in this study and I will not incur any expenses. I understand that in the event of injury resulting from research neither financial compensation nor free medical treatment is provided for such injury by the institution. I also understand that I am not waiving any rights that I may have for injury resulting from negligence of any person or institution.

8. Voluntary Participation: My participation in this research is voluntary. I understand that I may withdraw from this study at any time. My withdrawal from this study or my refusal to participate will in no way affect my care or access to medical services.

This is to certify that I consent to and give permission for my participation as a volunteer in this program of investigation. I understand that I will receive a signed copy of this consent form. I have read this form and understand the content of this consent form.

Volunteer's Signature ________________________ Date __________

I, the undersigned, have defined and explained the studies involved to the above volunteer.

Investigator's Signature ________________________ Date __________

Appendix B

Demographics Questionnaire

1. ID number ____________________

2. Gender of caregiver: ______(1) Male _____(2) Female

3. Age of the caregiver: ________________

4. Race of the caregiver: __________(1) African American

__________(2) Hispanic

__________(3) Asian

__________(4) Caucasian

__________(5)other ____________________

5. Number of years of education (caregiver): _________________

6. Employment status of the caregiver: _____(1) employed ____(2) not employed

____(3) retired

7. Do you have any other source of income in addition to your primary employment?

_______ (1)Yes _______(2) No

8. Marital status: _______ Married ________ Single ________ Divorced

_______ Separated ________ Widowed

9. Religion: _______Catholic ________ Prostestant ________Jewish

_______Muslim ________ Other: _________________

10. Do you live in the patient's household? ______(1) Yes ______(2) No

Who else lives in the household? ___________________________________

How old are they? ___________________________________

Do they aid in caregiving? ___________(1)Yes ___________(2) No

11. Relationship to the patient: _______(1) spouse or significant other

_______(2) child

_______(3) sibling

_______(4) friend

_______(5) other __________________

12. Number of years you have had a relationship with the ALS patient:___________

13. When was the ALS person diagnosed? (month/year): ______________

14. Number of months or years you have been the primary caregiver: _____________

Appendix C

DAS

(for spousal caregivers)

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	All of the time	Most of the time	More often than not	Occasionally	Rarely	Never
1. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	0	1	2	3	4	5
1a. How often did you discuss or considered divorce **before** the diagnosis of ALS?	0	1	2	3	4	5
2. How often do you leave the house after a fight?	0	1	2	3	4	5
2a. How often did you leave the house after a fight **before** the ALS diagnosis?	0	1	2	3	4	5
3. In general, how often do you think that things between you and your mate are going well?	0	1	2	3	4	5
3a. **Before** the ALS diagnosis?	0	1	2	3	4	5
4. Do you confide in your mate?	0	1	2	3	4	5
4a. **Before** the ALS diagnosis?	0	1	2	3	4	5
5. Do you ever regret that you married, or lived together?	0	1	2	3	4	5
5a. **Before** the ALS diagnosis?	0	1	2	3	4	5

	All of the time	Most of the time	More often than not	Occasionally	Rarely	Never
6. How often do you and your mate quarrel?	0	1	2	3	4	5
6a. **Before** the ALS diagnosis?	0	1	2	3	4	5
7. How often do you and your mate "get on each other's nerves"?	0	1	2	3	4	5
7a. **Before** the ALS diagnosis?	0	1	2	3	4	5
8. Do you kiss your mate?	0	1	2	3	4	5
8a. **Before** the ALS diagnosis?	0	1	2	3	4	5

9. The numbers on the following line represent different degrees of happiness in your relationship. The middle point, "happy", represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

9a. Now rate your degree of happiness in your relationship **before** the ALS diagnosis.

0	1	2	3	4	5	6
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

10. Which of the following statements best describes how you feel about the future of your relationship?

5_____ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.

4_____ I want very much for my relationship to succeed, and will do all I can to see that it does.

3_____ I want very much for my relationship to succeed, and will do my fair share to see that it does.

2 It would be nice if my relationship succeeded, but I can't do much more than I am doing

now to help it succeed.

1_____ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

0_____My relationship can never succeed, and there is no more than I can do to keep the relationship going.

Appendix D

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you:

	Not at all	Just a Little	Somewhat	Very Much
1. Believe that you've learned how to deal with a very difficult situation?	1	2	3	4
2. Feel that all in all, you're a good caregiver?	1	2	3	4

Think now of all the daily ups and downs you face as a caregiver; the job you are doing; and the ways you deal with the difficulties. Putting all these things together, how:

	Not at all	Just a Little	Fairly	Very
3. Competent do you feel?	1	2	3	4
4. Self-confident do you feel?	1	2	3	4

Appendix E

The primary caregiver of the person with ALS is the person who provides the majority of daily care for the ALS patient, but does so informally (i.e., is not paid to provide the care). The following questions ask about the amount and type of care you are currently providing as the primary caregiver for the person with ALS.

1. Thinking of all the help that you provide, how many hours do you spend in an average week providing care?

   1 _______ 0-8 hours per week
   2 _______ 9-20 hours per week
   3 _______ 21-40 hours per week
   4 _______ 41 or more hours, or "constant care"

2. Please check off all activities that you help the person with ALS perform:

   _____ Getting in and out of bed and chairs
   _____ Getting dressed
   _____ Getting to and from the toilet
   _____ Bathing or showering
   _____ Continence care with bowel or bladder or use of diapers
   _____ Assistance with feeding
   _____ I do not help with any of these

3. Please check off all activities that you help the person with ALS perform:

   _____ Managing finances
   _____ Housework
   _____ Preparing meals
   _____ Transportation (driving or arranging for transportation)
   _____ Arranging and supervising outside services
   _____ Grocery shopping
   _____ Giving medications

Appendix F

McGILL QUALITY OF LIFE QUESTIONNAIRE

STUDY IDENTIFICATION #:________ DATE: ________

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.
Please circle the number between 0 and 10 which is most true for you.
There are no right or wrong answers.
Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING *JUST IN THE PAST TWO (2) DAYS*.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - *over the past two (2) days* the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

Please continue on the next page...

PART B: Physical Symptoms

(1) *For the three (3) questions in Part "B", please list the* three (3) PHYSICAL SYMPTOMS *which have been the biggest problem for you over the past* two (2) *days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating. Feel free to refer to others if necessary).*

(2) *Circle the number which best shows how big a problem each one has been for you OVER THE PAST TWO (2) DAYS.*

(3) *If, over the past two (2) days, you had* NO *physical symptoms or only one or two, answer for each of the symptoms you* have *had and write "none" for the extra questions in Part B, then continue with Part C.*

1. Over the past two (2) days,
one troublesome symptom has been:______________________________.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

2. Over the past two (2) days,
another troublesome symptom has been:______________________________.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

3. Over the past two (2) days,
a third troublesome symptom has been:______________________________.
(write symptom)

no problem 0 1 2 3 4 5 7 8 9 10 tremendous problem

PART B: Physical Symptoms

(1) *For the three (3) questions in Part "B", please list the* three (3) PHYSICAL SYMPTOMS *which have been the biggest problem for you over the past* two (2) *days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating. Feel free to refer to others if necessary).*

(2) *Circle the number which best shows how big a problem each one has been for you OVER THE PAST TWO (2) DAYS.*

(3) *If, over the past two (2) days, you had NO physical symptoms or only one or two, answer for each of the symptoms you have had and write "none" for the extra questions in Part B, then continue with Part C.*

1. Over the past two (2) days,
one troublesome symptom has been:______________________________.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

2. Over the past two (2) days,
another troublesome symptom has been:______________________________.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

3. Over the past two (2) days,
a third troublesome symptom has been:______________________________.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

4. Over the past two (2) days I have felt:

physically terrible	0	1	2	3	4	5	6	7	8	9	10	physically well

PART C *Please choose the number which best describes your feelings and thoughts OVER THE PAST TWO (2) DAYS.*

5. Over the past two (2) days, I have been depressed:

not at all	0	1	2	3	4	5	6	7	8	9	10	extremely

6. Over the past two (2) days, I have been nervous or worried:

not at all	0	1	2	3	4	5	6	7	8	9	10	extremely

7. Over the past two (2) days, how much of the time did you feel sad?

never	0	1	2	3	4	5	6	7	8	9	10	always

8. Over the past two (2) days, when I thought of the future, I was:

not afraid	0	1	2	3	4	5	6	7	8	9	10	terrified

9. Over the past two (2) days, my life has been:

utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	very purposeful and meaningful

10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:

made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	progressed to complete fulfillment

11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:

completely worthless	0	1	2	3	4	5	6	7	8	9	10	very worthwhile

12. Over the past two (2) days, I have felt that I have:

no control over my life	0	1	2	3	4	5	6	7	8	9	10	complete control over my life

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree	0	1	2	3	4	5	6	7	8	9	10	completely agree

14. To me, the past two (2) days were:

a burden	0	1	2	3	4	5	6	7	8	9	10	a gift

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place	0	1	2	3	4	5	6	7	8	9	10	caring and responsive to my needs

16. Over the past two (2) days, I have felt supported:

not at all	0	1	2	3	4	5	6	7	8	9	10	completely

Please continue on the next page...